Mental Stability and Environmental Stressors:

Clustered Housing Needs Assessment

Merinell E. Thomas

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Accepted by the Graduate Faculty, Indiana University, in partial fulfillment of the requirements for the degree of Master of Arts.

John L. McIntosh, Ph.D.

Thesis Committee

V. Thomas Mawhinney, Ph.D.

Catherine Borshuk, Ph.D.

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Abstract

This study explored the challenges given communities in implementing the Olmstead vs. L. C. ruling that specifies that goods and services shall be afforded to an individual with a disability "in the most integrated setting appropriate to the needs" of the individual (paragraph 1) with special emphasis on the Clustered Housing Model (Olmstead v. L.C, 1999). To assess consumers' desires in choice of housing and services, questionnaires were completed by (1) members of the local National Alliance for the Mentally Ill, (2) Indiana University students, and (3) focus groups. Additionally, three focus group sessions met to discuss current housing needs and provide input on the Clustered Housing model. The responses of mental health service consumers were compared to the responses of those who had a loved one with a diagnosis of mental illness. The Clustered Housing Model was endorsed by all groups and was favored above all others for future housing development. Participants identified Privacy, Empowerment, Affordability, Individuality, Socialization, Location, Comfort, and Security as the most important needs for future housing consideration. Consumers and general respondents differed as to the degree of mental health support services needed to convey an individual's sense of integration into community. On the basis of the positive reception of the proposed model, this study suggests further research with regard to empowering consumer preference and housing design that reinforces a sense of community integration yet allows for a level of supportive services that is individualized according to consumer need.

Acknowledgements

This paper is dedicated to mental health consumers in St. Joseph County. Over and again they gave testimony to an Olmstead Initiative that has freed them from state institutions that were far from family and friends and has given them hope to lead normal lives within our community setting. They shared their dreams, as well as their fears, and their voices echoed all Americans. They dreamed of living in homes that were safe. They longed for the right to make informed decisions. They wanted to be able to express themselves and to be understood.

This study was born out the frustration of observing the shortage of housing for this population over many years. Encouragement to implement change came from my academic advisor, Dr. John L. McIntosh, and my thesis committee members, Drs. V. Thomas Mawhinney and Catherine Borshuk, to whom I am grateful. Thank-you for your interest and always timely advice.

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MENTAL STABILITY AND ENVIRONMENTAL STRESSORS: CLUSTERED HOUSING NEEDS ASSESSMENT

Since the mid-1950s, the total number of people with mental illnesses in state psychiatric hospitals throughout the United States has been reduced by 92 percent (Torrey, 1997, p. 9). The intent of this de-institutionalization was to reintegrate mentally ill persons back into their communities. In 1999, the landmark Olmstead decision was handed down by the Supreme Court and required that states, under the Title II of the American with Disabilities Act (ADA), place qualified individuals with mental disabilities in community settings. Each state was to develop a plan to "reasonably accommodate" (paragraph 3) these placements, taking into account their resources. Furthermore, they were to administer their services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals. The Court made two assumptions in this ruling. 1). People with mental disabilities are capable or worthy of participating in community life. 2). Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment (Olmstead v. L.C., 1999).

According to the Surgeon General one in five Americans in the general population experiences mental illness (U.S. Dept., 2001). The degree to which their symptoms affect daily living tremendously varies from individual to individual (Mowbray & Holter, 2002).), with some gaining recovery with current treatment methods. Others are able to manage with community support services, such as case management (Stromwall & Hurdle, 2003). Studies have shown that certain populations

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are at more risk for mental illness. Data on lifetime prevalence of DSM-III mental disorders from various epidemiological studies carried out on homeless populations indicate approximately one in three suffered from some kind of mental disorder (Gonzalez, Gonzalez, & Fernandez-Aquirre, 2001). That data corresponds with studies indicating approximately one-fourth of our local homeless population suffers from chronic mental illness (see Rumbach, South Bend Tribune, 12/11/01).

Unfortunately, the growth in affordable, safe housing has not risen with increased need. According to President Bush's New Freedom Initiative Mental Health Commission's report (Faith, 2003), the lack of decent, safe, affordable, and integrated housing is one of the most significant barriers to full participation in community life for people with serious mental illnesses. Today, millions of people with serious mental illnesses lack housing that meets their needs. This shortage of affordable housing and accompanying support services is a contributing factor causing people with serious mental illnesses to cycle among jails, institutions, shelters, the streets, or to live in seriously substandard housing.

Fortunately, recent studies have shown that, given stable housing with support, the mentally ill can and do thrive within their communities. For example, California, conducting community intervention studies in Los Angeles, Sacramento, and Stanislaus counties, found that using a combination of less debilitating medications and the promise of adequate housing alternatives has been able to get people off the street and induce them to stay in treatment (Reyes, 2000).

In 2000, the Department of Human Services convened two stakeholder meetings to provide solutions to the dilemma posed by the Olmstead v. L.C (1999) ruling that specifies that goods and services shall be afforded to an individual with a disability "in the most integrated setting appropriate to the needs" of the individual. (paragraph 1) According to the Olmstead Housing Working Group Report, several key areas of importance pertinent to housing the disabled (including mental health consumers) were identified, including: housing accessibility, housing integration, affordability and financing, and consumer choice in housing (Paulauski, 2000). The current study identified current housing options available to mental health consumers and outlined the right of choice in housing afforded to mental health consumers by law. Below is examined the veracity of cost effectiveness and housing integration to see whether they fit the de-segregation strategy. The clustered housing model is offered as an alternative to current housing options. Additionally, the current study examined current National housing options for mental health consumers and compared them with local need and housing availability. Consumer input on the Clustered Housing option was gathered using survey and focus group methods. Results were reviewed within the theoretical frameworks of stress theory, social support theory, and locus of control.

Clustered Housing Option

The focus of this study was to assess the need for clustered housing for mental health consumers in St. Joseph County and to develop specific goals and objectives to address this need. Several other regions across the nation have successfully incorporated clustered housing into their continuum of care for mentally ill residents. Currently, St. Joseph County has no such facility. "Clustering" measures the extent to which units

inhabited by minority members adjoin one another, or cluster, in space (Massey & Denton, 1984, p. 149). Massey and Denton used this term in reference to spatial proximity of racially diverse segments of population. This study would argue that mental health consumers are a special minority which constitute a unique minority with similar needs.

There are several models of clustering that are available from which to draw guidance. First, the Netherlands' system of care for the mentally ill has in place a three-part system of residential care and independent living for people with disabilities, including the clustered model. The three-part system comprises: The residential center model, the clustered housing model, and the independent housing model (DeJong, 1984). The difference in models is the level of care and support needed for the individual to function at potential, with the clustered housing model providing a median of care.

Closer to home, starting in 1998, DuPage County in Illinois obtained funding for two clustered housing apartment sites with another 12 units planned for the future (DuPage, 1998). Also in 1998, the National Symposium on Homelessness Research advocated for the adoption of a clustered housing model to provide "next step" housing for mental health consumers who have graduated from congregate homeless facilities but can benefit from continued support. Under this model, the individual living units would have single or double bedrooms but share common living, kitchen or bathroom space. Staff is on-call to provide crisis services. This model allows for case management, as needed, to monitor the ability to handle daily living stressors. Residents are expected to "graduate" to fully independent non-clustered housing in the broader community (Barrow & Zimmer, 1998, paragraph 5).

In another example, HUD provided the city of Bucyrus, Ohio a capital advance of $1,164,000 and a five-year rental subsidy of $242,000 to construct 14 one-bedroom apartments for persons with chronic mental illness with an in-house resident manager (HUD, 2004). In yet another model of clustered type housing, the city of New York (2003) is currently testing the merger between a "housing as housing" model for housing consumers and an "integrated housing development" model (Hopper & Barrow, 2003, p. 50). The housing as housing model seeks to find "less-structured alternatives to clinically managed residential programs" (p. 50), usually in the form of separate integrated housing units with mental health service supports, while integrated housing development attempts to preserve and create affordable housing by building low-income community housing developments. The merger of the two models would preserve consumers' right to receive housing and services in "as normalized a setting as possible" conducive to mental stability. (p. 53)

As a final example, the city of Eugene, OR developed a 35 unit clustered housing complex for individuals with severe and persistent mental illness. In this model, apartments are clustered in groups of four around central common rooms, including a central kitchen, a program office, and meeting area. A case manager assists with support services, as needed (Shelter Care, 2004).

Levels of Care Model

According to information from the National Resource Center, models of clustering fall into two categories: the "high demand" or "low demand" approach (Barrow & Zimmer, 1998, paragraph 3). High demand service-intensive programs using clustered housing settings provide services on-site, where participation and compliance

with treatment can be encouraged and monitored. Low demand programming operates with the expectation that residents will access mainstream services in the larger community. This model operates in an either/or mode. Residents are either low demand service consumers or require high demand care.

Cost Effectiveness

While legislation has made it clear that "lack of funding" (Olmstead, 1999, paragraph 2) cannot in itself serve as an excuse for non-provision of quality mental health services, communities must search out service models that provide the ultimate of care, while attending to cost effectiveness. Keeping in mind funding constraints, new models should be no more costly than the system that was in use before (Bond, Drake, Mueser, & Latimer, 2001). The Barnard-Columbia Center for Urban Policy Cost report defined cost effectiveness as the relative cost of achieving different levels of outcome (1996). Cost effectiveness in the current study relies on measures of service utilization in order to assess costs associated with providing mental health services. Identified costs include housing, case management services, staffing, and self-sufficiency education.

Additional studies have shown that it is physically cost effective to construct clustered housing, as systems such as septic, green-spaces, and sidewalks are shared. In 2004, President Bush has set aside energy grants in collaboration with the U.S. Dept. of Energy to create energy smart communities in which he is encouraging communities to establish tax credits, offer rebates, low-interest loans, and other incentives for energy-efficiency improvements (U.S. Dept. of Energy, 2004). Clustered housing could utilized these incentives and pass on the savings to consumers.

The State of Indiana is in the planning stage of creating energy incentives for taxpayers with Governor Kernan signing the Greening the Government initiatives on September 13, 2003 (Executive Order 03-27). Additionally, monies are available through HUD to finance the acquisition, rehabilitation, or construction of housing intending to be used for persons with disabilities. By combining HUD and Medicaid Waiver monies services such as Case Management, medication monitoring, on-site meals, socialization activities, and non-medical counseling can be provided on-site, eliminating the costly transportation costs charged to Medicaid via Roadrunner, American Ambulance, or taxi-services (see "Current Funding Options" section for more on HUD and Medicaid Waiver services).

The current system of mental health support in St. Joseph County relies on a multifaceted service provision with levels of care variation dispersed throughout the county at high cost to taxpayers. Consumers must travel to mental health centers to receive services or have case managers visit their homes. There are waiting lists for subsidized housing and traditional housing is beyond the financial capabilities of many consumers. Utilizing the cost effective housing measures being developed in other communities would save taxpayer monies and provide consumers with a viable alternative to current housing.

Community Integration

While the intent of de-institutionalization was to integrate mental health consumers into local communities, the current model of group homes, county homes, and dormitory type housing serves to isolate rather than integrate many consumers. For example, Portage Manor, funded by St. Joseph County taxpayers, houses 144 residents

under one roof. Of that number, approximately 130 residents have severe mental illness (correspondence with Charles King, February 2004). Most beds within the facility are located in wards, with 3-4 residents per room. Social interaction for the residents is mostly in-house with other mental health consumers. It could be argued that rather than integrate, Portage Manor and group homes segregate residents from the community.

Theoretical Frameworks for Study

Stress Theory

Stress theory maintains that stressors from the physical and social environments create a state of internal arousal or strain that has negative consequences on health (Miller, 1989, p. 52). There is increasing clinical and research evidence that stressful life events, traumas, and major losses may have a profound and detrimental impact on physical and mental health status (Kessler, 1997). Furthermore, studies have suggested that stressful life events have a substantial causal relationship with the onset of episodes of certain mental illnesses (Brown & Harris, 1989; Dept. of Health and Human Services, 2004; Kendler, Karkowski, & Prescott, 1999). Many such studies have been conducted in the past two decades and there is a consistently documented association between exposure to stressful life events and subsequent onset of episodes of major depression. However, the magnitude of this association varies across studies depending on how life events are measured, with associations generally stronger when "contextual" measures are used rather than simple life event checklists (Kessler, 1997, p. 193).

Further studies have suggested that continued stress in individuals who are perpetually discriminated against, such as the mentally ill, might exacerbate symptoms (Marano, 1999). According to Sims and Victor, (1999), homeless people experience

twice the rate of neurotic disorder in association with stressful life events. The correlation between homelessness and increased symptoms suggests that unstable housing may be a leading stressful life event for this population. The current study is based on the premise that consumers will identify housing instability as a leading life stressor affecting mental stability.

Social Support Theories

While the use of adjusted stressful life events scales has established a relationship between stressors and health in a variety of populations (Mohr et al., 2000; Watson, 1998), research has indicated that adequate social support appears to buffer the effects of stressful life events (Alloway & Bebbington, 1987; Fitzsimon & Fuller, 2002). For example, while recent studies identified the lack of social support as one of the leading stressful life events in patients suffering from major depression (Skarsater, Agren, & Dencker, 2001; Tennant, 2002) others suggest that the impact of stressful life events involving social networks may be buffered by satisfying relationships with close friends and relatives (Aneshensel, 1992). Furthermore, Chou and Chi (2001) reported decreases in levels of depression as individuals perceived an increased sense of personal control and social support.

In a review of studies on the buffering effects of social support, it is expected that the need for supportive environments will emerge as a leading factor influencing consumers' housing decisions. For example, it is expected that consumers will identify the need to maintain close proximity with friends as one of the leading factors in housing satisfaction. Additionally, lack of mobility, isolation from peers, inadequate access to

private phones lines, and forced interaction with strangers are expected to emerge as factors associated with unsatisfactory living situations.

Coping Strategies

Finally, coping strategies may play a role in susceptibility to mental instability. There are several theories that attempt to explain how people view the social world and how they cope with life stressors using their personal vantage point. One of the leading theories is the locus of control hypothesis. According to Rotter, locus of control is an expectation concerning the likelihood that one's behavior will lead to desired social outcomes (Rotter, Chance, & Phares, 1972, p. 260). Past research has noted a relationship between the perception of control and health, equating belief in control as beneficial and perceived lack of control as detrimental (see McLaughlin, & Saccuzzo, 1997, p. 269). People who believe factors beyond their control (e.g., luck, circumstances, or influential others) determine social outcomes are said to have an external locus of control. Those who believe that their own behavior causes their current social situations are said to have an internal locus of control. Liu and Hiroshi (2000) found a positive correlation between negative life events, high life stress score and high external locus. In the past, external pressure from society, via institutions, was placed on mental health consumers. This imposed external locus is being challenged. Rapp (2000) argued that care and treatment of people with severe mental illness should include consumer empowerment. (p. 730) The empowerment model prioritizes the participation of the individual in any choices affecting welfare and, in this case, choice of housing (Fitzsimons & Fuller, 2002; Stromwall & Hurdle, 2003). Thus, empowerment removes the locus of control from institutions and allows consumers the health-enhancing role of participating in their

community (Lord & Hutchison, 1993). Not all theorists agree with this philosophy. In a study by Warren and Bell (2000), consumers rejected congregated housing because it enabled the larger community to more easily identify them as former psychiatric patients.

This study would argue that increasing the housing options for mental health consumers to accommodate for their defined needs, would provide an increased feeling of control, thereby, reducing stress and enhancing well-being.

Housing Mental Health Consumers

Current National Effort in Housing Mental Health Consumers

Since the 1999 decision, revisions have been made to the Olmstead initiative. Congress passed the American Homeownership and Economic Opportunity Act of 2000 (AHEOA), which permitted recipients with disabilities to use up to a year's worth of vouchers to finance the down payment on a home (H.R. 1776: AHEOA, 2000). In 2001, President George Bush issued the Olmstead Executive Order making Workforce Actions Grants available to states to implement the Olmstead decision. In that same year, he launched the New Freedom Initiative (NFI) to help remove "barriers to full participation in community life" (Investing in, 2001, slide 9) and provide new freedom for America's disabled seeking access to work, education and worship. The NFI built on the Americans with Disabilities Act by increasing the community role of people living with disabilities (Harkin, 2001, paragraph 2). In the words of President Bush, "Old misconceptions about physical and mental disability are being discredited. We must speed up the day when the last barrier has been removed to full and independent lives for every American, with or without disability" (Bush, 2001, paragraph 7). With special focus on consumers' needs he sanctioned the National Commission on Mental Health Services in 2001 (Enda) and, in

2002, the President's New Freedom Commission on Mental Health (DeStefano, 2004). Meanwhile, the Center for Mental Health Service (2002) issued a report that emphasized consumer choice through the process and identified the leading barrier to implementation as a "lack of community housing" (Holsapple, 2003, slide 5). In response, President Bush signed legislation increasing by $1.2 billion the FY 2002 budget for state grants (DeStefano, 2004) in "fulfilling America's promise" to help transition Americans with Disabilities from institutions to community living (Progress Report, 2004, chap. 4). Finally, he introduced a bill to provide future funding through the Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) program and proposed, beginning on July 1, 2006, that an individual who is an eligible for the CHOICE program shall not remain on a waiting list for services for more than 90 days (House Bill 1305, 2004).

While this initiative is admirable, individual states struggle to meet the public demands for community-based programming. For example, since 1994, the state of Michigan, using the philosophy that even severely impaired persons can successfully reside in community settings, has dedicated itself to the placement of persons diagnosed with mental illness from state-operated inpatient facilities to community settings, with the provision of support services to those individuals (see Mastering community, 2001). Philadelphia upheld a recent challenge to the granting of a Fair Housing Accommodation Request on behalf of their mentally ill residents (Cramer & Moss, 2000). According to officials at the National Mental Health Association, Cambridge, MA is providing a variety of housing and support services for people with mental illness including implementation of a cultural model that addresses the needs of Spanish-speaking

consumers (Buckner, 2000). In 2001, Texas legislators passed Rider 37, which ties long-term care money to the individuals receiving services, enabling approximately 2000 people to integrate into their communities and out of institutions (Donlin, 2003).

States that fail to comply with legislation are facing public pressure to reform. Although, the Fair Housing Act was amended in 1989 to include people with disabilities, municipalities have been slow to take the law seriously. Recently the District of Columbia was warned that its "neglect of mental health consumers" would lead to legal action if not addressed immediately (see New DC Receiver, 2000). Furthermore, lack of adequate funding for services does not dismiss a state's responsibility to provide services, as New York state officials discovered with passage of Kendra's Law, the state's new outpatient commitment law that mandates that the mentally ill receive treatment (see Kendra's Law, 1999; New York officials, 2000). In 2003, disability rights advocates filed suit in the United States District Court against New York officials on behalf of approximately 4,000 individuals with serious mental illnesses alleging that New York State is unlawfully segregating individuals (see Lawsuit seeks, 2003). In another instance, a federal judge in Illinois ruled that the city of Chicago Heights violated the Fair Housing Act in its refusal to grant a special-use permit to a mental health services provider who sought to build a group home in the city (see U.S.A. v City of Chicago Heights, 1999).

Indiana's Current Effort in Housing Mental Health Consumers

A 2002 report issued by the Governor's Commission on Home and Community-Based Services admitted Indiana continued to lag behind the rest of the country in providing affordable housing and sufficient in-home and community-based service options for the disabled. As a result of this study Indiana applied for and received three

federal grants to assist in overcoming the long-standing barriers that had made reform so elusive. Of these, the Real Systems Change Grant provided for mini-grants to be available to communities to fund Olmstead integration practices (see Governor's, 2002).

The actions of Indiana lawmakers have not gone unnoticed. In August 2003, the National Council on Disability released an analysis of state and federal implementation of the Supreme Court's Olmstead decision commending Indiana's implementation plan (Informing Indiana, 2003, paragraph 16). Indiana continues to push for consumer's rights. Proposed legislation in 2004 include: House Bill 1164, a nonnutritive beverage tax with revenue targeted in the long term care continuum fund to allow individuals with disabilities to live in the community of their choice, and House Bill 1005, to established the Local Government Finance Study Commission to review the impact of tax increases at the local level to support local services (Fulford, 2004). Soon, public hearings will begin to draft the 2004-2007 State Plan for Independent Living to outline how we will uphold the philosophy of independent living as we continue to integrate individuals with significant disabilities into the mainstream of Indiana's communities (S. Res. 363, 2004).

In the effort to comply with legislation, some municipalities have resorted to converting previously retirement homes or large old family dwellings in decaying neighborhoods into board and care operations (Lesage & Morrissette, 1993). While existing board and care facilities remain important for psychosocial rehabilitation because of scarcity of housing alternatives (Pulier & Hubbard, 2001), they may lack the very community support systems that are imperative to consumer integration. Consumer satisfaction surveys have shown that individuals with psychiatric disabilities prefer life in the community. Lack of medical care and social isolation continue to pose wellness

obstacles in integration into the community (Davidson, Hoge, Merrill, Rakfeldt, & Griffith, 1995). The following section describes the facilities currently available to local mental health consumers.

Current Housing Options for Consumers in St. Joseph County

While primary care shifted from inpatient facilities to the community for hundred of thousands with severe mental illnesses, not all communities had adequate housing or support services to meet that demand (Sherry, 2001). According to the first Surgeon General's Report on Mental Health, mental disorders are experienced by one in five Americans (U. S. Dept., 2001). The US Census Bureau Data Set estimated Saint Joseph County at a population of 264,779 (U.S. Census, 2001). Using those estimates, mental illnesses may directly affect as many as 53,000 persons in St. Joseph County. That figure soars when considering family members of the afflicted who are indirectly affected. The Consolidated Plan for the State of Indiana in 2004 does not cover housing and community development funding in St. Joseph County. Local plans do (see Consolidated Plan, 2004).

In 1996, an extensive study (the MAP Project) was conducted by the Task Force on Housing for Disabled and Disadvantaged Citizens to assess the variety of existing housing and services for the disabled and disadvantaged citizens in the South Bend, Mishawaka, and St. Joseph County communities (Bauer & Amico, 1996). The MAP Project identified private as well as public housing, the administering agency, a profile of residents, location of residences, residential capacity, numbers served annually, and funding sources. While the MAP Project did not specifically target mental health consumers, it provides a starting point in referencing this population.

While St. Joseph County has an extensive network of services targeted for the disabled, the MAP Project findings illustrated that there are few housing options for the mentally disadvantaged. There are only six organizations that provide services to individuals with mental disabilities. The Pejus, Inc. organization provides services exclusively to mentally retarded individuals, which reduces service providers to consumers of mental health services to five. Out of these five, four types of housing were identified. The current study examines the advantages and disadvantages of each type of housing option identified by the MAP Project and compares results to a clustered model option.

Existing housing facilities for mental health consumers in the community range from single centralized building facilities with many services and housing accommodations such as the Center for the Homeless, Hope Rescue Mission, and the YWCA, to an organization with a variety of facilities, such as Madison Center, which offers housing options consisting apartments for semi-independent living and several group homes located throughout St. Joseph County.

This study has identified four basic housing types among mental health consumers in Saint Joseph County: (1) campus complexes, (2) dormitory or hotel type buildings, (3) apartment and town house type buildings and complexes, and (4) group homes. A brief discussion of each type of housing with applicability to this study follows.

Campus Complexes

Campus complexes are comprised of a variety of separate buildings and services including housing located in a campus like setting near residential and commercial areas. The Family and Children's Center campus has three residential buildings divided into

three dormitory style cottages housing 19 students each. The campus includes classrooms, a dining hall, a recreation hall and an outdoor area. The Center serves emotionally disturbed children in a highly structured and supervised environment. While this multifaceted complex closely resembles the clustered housing model proposal in proximity criterion, this study seeks to establish permanent housing options for mentally ill residents. As this facility is restricted to a limited segment of the population (i.e., juvenile residents, emotionally disturbed vs. chronically mental ill) on a temporary basis, it is not counted in current available housing totals.

Dormitory Buildings

Dormitory type buildings are located in multi-family residential and commercial areas. Housing is provided within a single building which has a variety of services including dormitory type sleeping accommodations and a dining room. This type of facility provides for a supervised living environment. The Center for the Homeless, Hope Rescue Mission, Portage Manor, and the YWCA are examples of organizations that have facilities of this type.

Center for the Homeless. The purpose of the Center for the Homeless is to provide temporary shelter until a more permanent placement can be found. According to the senior operating office, the St. Joseph County Center for the Homeless houses approximately 191 individuals per night with a total capacity of 118 single beds in a dorm setting and 22 family dormitories (T. Oehm, personal communication, February 10, 2004). Recently they expanded their residential capacity to meet the need for housing. Even with the recent expansions, the Center for the Homeless turns away approximately 12 applicants monthly, due to lack of beds (Ms. Moorelock, Social Services Coordinator,

personal communication, June 9, 2003). This is not just a South Bend phenomenon. A survey of 27 U.S. cities found that requests for emergency shelter increased by an average of 13 percent in 2001 and requests for shelter by homeless families alone increased by 22 percent (Who is Homeless, 2002).

As The Center for the Homeless is housed under one roof, it resembles a clustered housing option in services only.

Hope Rescue Mission. The Hope Rescue Mission provides services to homeless individuals without regard to mental health status and does not provide direct services to mental health consumers. There are no known studies to indicate that their population differs from other homeless centers' statistics. For this study, it is assumed that one third of their population suffers from mental illness and could benefit from housing targeted to that population. The Hope Rescue Mission provided services to 1301 people in 2002 (C. Manning, personal communication, February 4, 2004). It is estimated that 2003 service numbers will be similar. As the Hope Rescue Mission is housed under one roof, it resembles a clustered housing option in services only.

Portage Manor. Portage Manor is a residential facility owned and operated by St. Joseph County that at full capacity can provide housing for approximately 144 residents. Of that figure, approximately 130 beds are available for chronically mentally ill persons. The rest are reserved for mentally retarded individuals, endangered adults, or the fragile elderly who do not qualify for nursing home placement. Portage Manor provides medication monitoring via 24-hour nursing staff, dining room meal service, laundry service, and recreational opportunities. As Portage Manor residents are housed in one large building, it resembles the clustered model in services only. According to the

director of the facility from November 2001 to February 2003, no new residents were being admitted to this residential facility due to a State ordered freeze in residential funding (L. Becker, personal communication, July 2003). This freeze in residential placement was imposed 11/21/01, by the Indiana Family and Social Services Administration (FSSA), to prevent program costs from exceeding the amount appropriated for it, in the state budget. According to Marilyn Schultz, director of the FSSA Division of Disability, Aging and Rehabilitative Services, costs for housing the disabled have doubled since 1993, but appropriations approved by state legislators have not kept pace with that growth (Rumbach, 12/11/01). Since the freeze was lifted, agencies like Portage Manor have competed for limited State residential funding, filling resident beds as funding becomes available.

Y.W.C.A. The Y.W.C.A. of St. Joseph County provides temporary housing, social and educational services for economically disadvantaged women in the community under the three divisions of Chemical Dependency, Self-Sufficiency, and Domestic Violence. There is no evidence that mental health consumers are targeted for services. As this facility is restricted to a limited segment of the population (i.e., victims of domestic violence) on a temporary basis, it is not counted in current housing available totals.

Apartments

Apartment complexes are located in multi-family and single family residential areas. These complexes serve persons who can live independently and semi-independently. For instance, Madison Center, in cooperation with the South Bend Housing Authority and Real Estate Management, provides semi-independent (SILP) supervised living for mental health consumers. The facilities are subsidized and the

residents pay reduced rent and abide by leases similar to tenants of non-subsidized complexes. These units are similar in character to units for independent living and are integrated into the community. They are not in close proximity to other units housing mental health consumers, so they do not resemble the clustered housing model.

Madison Center Apartment Buildings. There are currently three apartment buildings housing exclusively mental health consumers: Gateway Apartments (25 units), Uhrig Apartments (20 units), and Madison Center Apartments (29 units). Each unit houses one resident (with the exception of one married couple at Uhrig Apts.). The units are similar to other efficiency apartments in the area with a bedroom, efficiency kitchen, and living area. According to the housing supervisor, one apartment in each building has a live-in staff person who provides moderated supervision on-site (S. Miley, personal communication, February 11, 2004). There is currently a waiting list of approximately 10 people. According to the director of the Madison Center SILP program, this number remains constant (S. Dale, personal communication, October, 23, 2003). The wait for an apartment may be as long as two years. Many candidates give up on the process before being placed. These apartment units approach the clustered housing option with case management services on-site, yet they fall short of the model as they are housed under one roof.

South Bend Housing Authority. Mental health consumers may qualify for housing assistance through the South Bend Housing Authority. There are several low-income apartment complexes through the St. Joseph County region managed by the South Bend Housing Authority. The South Bend Housing Authority does not discriminate against the mentally ill, but unfortunately for this study, there is no way to tell how many units are

occupied by this population. They do not fit the clustered housing model, as they do not provide any mental health services or support, so they are not counted in this study.

Group Homes

Group homes are single-family houses located in residential areas for people who are able to live semi-independently. There are currently three group homes exclusively housing mentally ill residents: Metcalfe House, Widener Place, and Harris House. Each home is integrated into a middle class residential area and houses 8 persons. Residents share a bedroom with a roommate. Household chores are shared and staff maintains 24-hour supervision. While the group homes resemble the services proposed with the clustered housing option, they lack proximity to other homes and services essential to the model.

Summarizing these housing options, therefore, the total number of current beds available for St. Joseph County mental health consumers is approximately 483 (see Table 1) with only 228 of those exclusively for mental ill individuals. It is obvious that need for housing outweighs availability. As many as 53,000 St. Joseph County residents may suffer from a mental illness, yet St. Joseph County can house only a fraction of that number with current resources.

Current Funding Options

"People with disabilities have the highest level of unmet need for housing assistance of any group eligible for federally subsidized housing assistance" (O'Hara, 2003, paragraph 3). Accordingly to O'Hara, approximately 3.7 million non-elderly people with disabilities rely solely on federal SSI benefits worth $545 per month. Our study indicates that at least 50% of participants received public funds with 40% utilizing

housing assistance. Below are detailed some of the funding options available in our community to meet housing need.

Medicaid Waiver Option

Medicaid Waivers are granted to housing providers to supplement rental incomes of the disadvantaged and provide incentives to house this population. Medicaid money goes from the state to the county agencies that administer the program. They are known as "waivers" because the federal government has waived certain regulations allowing funds to provide services that allow a disabled person to live in the community and avoid institutionalization (Dept. of Health, 2003, paragraph 1).

The waiver programs were authorized under section 1915(c) of the Social Security Act of 1981. According to the Center for Mental Health Services (CMHS) over 50% of all community mental health services are currently funded by Medicaid (CMHS, 2004) with as much as 25% going to housing people where they do not want to be (Jackson, Hafner, O'Brien, and Benjamin, 2003). The aim in granting waivers was to encourage community based treatment alternatives. In 1997, 211 Medicaid 1915 (c) Waivers were granted to landlords at a cost of $7.87 billion to aid 561,510 renters (NIDRR, 2001). By 1999 that cost had risen to $10.6 billion. This still pales in comparison to nursing home care, which costs Medicaid $36.4 billion (Fox & Kim, 2004).

Department of Housing and Urban Development (HUD)

Federal support for both transitional and permanent housing has been provided since 1994, when the U.S. Department of Housing and Urban Development (HUD) began to require that applicants for federal funds create an integrated continuum of care. Under

HUD's Section 811 Supportive Housing Program for Persons With Disabilities program, funding is provided to non-profit organizations to develop congregate living, including the acquisition, rehabilitation, or construction of housing intending to be used for persons with disabilities, including those with severe mental illnesses (Section 811, 2004). For 2001, funding of the HUD Section 811 program was $240.9 million. For fiscal year 2004, that figure has soared to $251 million (HUD, 2004). Additionally funding is available via the Congregate Housing Services Program to provide supportive services on-site to enable consumers to live as independently as possible (HUD, 2004). Section 8 Vouchers and Homeless Center Vouchers, funded by HUD, are available to consumers locally and are described below (HUD, 2003).

Section 8 Vouchers

While Medicaid Waiver Options are granted to landlords, Section 8 Vouchers are issued to the renter. In 1974, President Nixon created the Section 8 housing program and by 1997 1.5 million households received benefits under this program (NIDRR, 2001). In 2002, the VA-HUD bill expanded the existing allocation of Section 8 tenant-based vouchers for non-elderly adults with disabilities (including people with severe mental illnesses) by $40 million (NIDRR, 2001). In May 2000, the Indiana Housing Finance Authority (IHFA) was selected as the Contract Administrator for Housing Assistance Payments contracts in the State of Indiana. As of August 2002, IHFA has been responsible for the contract administration of 27,557 affordable rental units (IHFA, 2004). The Housing Assistance Office, Inc. administers the Section 8 Certificate and Voucher Programs for income eligible families in Mishawaka and in the outlying areas of St. Joseph County.

Homeless Center Vouchers

Residents at The Center for the Homeless can seek housing assistance via the Shelter Plus Care program. The Shelter Plus Care Program provides rental assistance for homeless persons with disabilities in connection with supportive services funded from sources outside the program (U.S. Dept of Housing, 2003). Supportive services are funded by Federal, State, or local, as well as, private sources. In 2002, funding for federal homeless programs under the McKinney-Vento Homeless Assistance Act was $1.02 billion with the requirement for states and localities to come up with a 25 percent local match when funding services with federal homeless dollars (NAMI, 2001). On December 19, 2003, the Bush Administration increased this amount to a record $1.27 billion (DeStefano, 2004). HUD uses a "Continuum of Care" approach to funding programs that serve the needs of persons who are homeless. Funds are used to prevent homelessness through rent/mortgage assistance, utility assistance and security deposits (Kernan, 2003). According to HUD, Indiana received over $17 million in Continuum of Care and Emergency Shelter Grants in 2003, with the South Bend Center for the Homeless receiving $312,000 to assist with housing the homeless (HUD, 2003).

Private Donations

As with the Homeless Center Voucher described above, many housing funding sources require matching funds from the targeted community. Since 1996 the Fannie Mae Foundation has provided funds to more than 2700 communities, contributing over $1 billion toward expanding affordable housing options (Blymire, 2002). In Washington, DC, the Anchor Mental Health organization raised $85,337 in support of the renovation of nine group homes for mental health consumers. Cornerstone, Inc., contributed $25,000

in funds to Washington, DC, in support of an organization that develops affordable housing with support services for persons with chronic and persistent mental illness. The *Grand Rapids Business Journal* reports that a grant from Grand Rapids Local Initiatives Support Corp. will help a group of local churches and community organizations convert the former Ferguson Hospital into apartments and supportive facilities for the physically disabled and mentally ill (LISC, 2000).

The current study has identified a few private sources of funding. Many more remain unidentified and come from private trusts, community fundraisers, and local businesses.

Exploring Clustered Housing Alternatives

This study explored the alternative of developing a clustered housing complex that embraces the levels of care model, housing low demand and high demand consumers within a community setting, similar to a retirement complex. Per the Olmstead coalition recommendations, preserved would be the consumers' right to choose to reside in this complex. The clustered housing option would include amenities, such as: the option to own, access to transportation systems via personal vehicle or Transpo bus, choice of dining options, voluntary participation in community or on-site activities, personal space, child care, supportive services, living skills training, employment training and job placement, medical/ mental health treatment, and a levels of care continuum. This would provide a stable environment where consumers could optimize their potentials and reduce stressors related to unstable or inferior housing (see "Stress Theory" in Theoretical Frameworks section). Cost effectiveness would be capitalized on by providing services on-site, per individual need. Additionally, consumers would have a say in the

community's decision-making processes, thus gaining a sense of ownership and control. Coping Theory model (see "Coping Theories" in Theoretical Frameworks section) would predict that this is likely to increase mental wellness. Mental health consumers would have a place of their own where they could entertain family and friends and not have to rely on other consumers or service providers to provide social interaction. The increased social support is expected to reduce symptoms and increase quality of living (see "Social Support" in Theoretical Framework section).

To gain a comprehensive understanding of the needs of mental health consumers in St. Joseph County this study included representatives from diverse sources and levels of functioning. This study examined consumers' housing needs from the perspective of the consumer and consumers' supporters (i.e., family members). Additionally, this study assessed consumer needs from different physical populations. For example, it was expected that students would identify different housing and service needs than the homeless. It was further expected that consumers of mental health services would identify different housing needs than supporters of consumers.

Three separate hypotheses were examined in the current study. First, it was premised that consumers will identify instability in housing as an ongoing source of stress when considering current housing options. Next, it is expected that consumers will identify the need to maintain close proximity with friends or family as one of the leading factors in housing satisfaction. Conversely, lack of mobility, isolation from peers, inadequate access to private phones lines, and forced interaction with strangers are expected to emerge as factors in unsatisfactory living situations. Finally, this study would argue that increasing the housing options for mental health consumers to accommodate

for their defined needs, would provide an increased sense of empowerment, thereby reducing stress and enhancing well-being.

Study 1: NAMI Survey

A survey of St. Joseph County members of the National Alliance of the Mentally Ill (NAMI) was conducted. With more than 210,000 members, NAMI is the nation's leading grassroots advocacy organization dedicated to improving the lives of persons with severe mental illnesses (NAMI E-News, 10/30/01). Additionally, the local branch provides support to mental health consumers and their loved ones through monthly meetings. Friendships are nurtured, information about resources is shared, and an informal support system is maintained. NAMI is active in advocating legislation supportive to treatment and protecting the rights of mental health consumers.

Method

Participants

The president of the St. Joseph County NAMI branch provided a mailing list of 99 members. Surveys were mailed to all members on this list. Additionally, survey forms were made available at the monthly meetings. NAMI members returned 25 completed surveys.

Materials

The *Consumer Satisfaction Survey: Assessment of Housing Needs of Mental Health Consumers in St Joseph County* was created and used in this study (see Appendix A). Survey questions were composed over a six-month period from interviews with local NAMI members at monthly meetings using an adaptation of grounded theory methodology (Charmaz, 2000). Grounded theorists contend that unless you have an

understanding of the cultural/social vantage of respondents, responses mean nothing. The researcher took notes on the narratives during each session.

"Consumer" was defined in the questionnaire as an individual who has been diagnosed with a DSM-IV mental illness or has been treated for mental illness within the past five years (see American Psychiatric Association, 1994). Question 1 asked participants to identify whether they were "mental health services consumers." The participants that selected that response (Q1.1) are referred to as *consumers* for purpose of analysis. All other responses are referred to as *general responses.* For example, *general responses* would include responses from a family member, guardian, or friend of a consumer. Questions 2-11 asked the participant to respond on behalf of the consumer. "Don't know" was included as a response choice if they were unsure of how the consumer might answer. Question 12 asked for the participants' opinions in housing preference. A demographic characteristics box recorded information on gender, race, and age of consumer.

Additionally, the first part of this survey tool was developed after careful review of current service options attached to available local housing. Questions assessing "consumer's current housing status" and current housing "financial assistance" set the stage for examination of alternate options which were contained in the Clustered Housing Option section of the questionnaire.

The Clustered Housing Option (Q12) section of the survey tool incorporated components of clustered housing models found outside of this community. Participants were offered several choices of housing options and asked to indicate their preferences.

Choices ranged from "single family housing integrated within the community" to "multilevel care housing complexes."

Procedure

The St. Joseph County National Alliance for the Mentally Ill (NAMI) association provided a mailing list of members. The study questionnaire was mailed to all members on the local NAMI mailing list. Additionally, the researcher attended monthly NAMI meetings, and made the survey available to the attendees. The survey packet contained the questionnaire form, an informed consent form (Appendix B), and a stamped addressed return envelope. No incentive was provided other than the contribution to the knowledge base on this important issue. Participants demonstrated their willingness to participate in this study by returning the completed questionnaire and informed consent form in the stamped addressed return envelope included in the survey packet.

Results

The data was entered into an SPSS 11.5 worksheet and analyzed to identify which mental health services are most valuable to NAMI members. Of the 25 respondents, 16 males and 8 females identified gender. The responses of *consumers* (5) were compared to *general responses* (20).

What is the consumer's current housing status? (Q2, Q3)

According to the *general responses*, at least 58% of respondents were living in some sort of supportive environment, either living with relatives or involved with the Supported Independent Living Program. Only one individual owned a home. Approximately 42 % were living alone. Of the *consumers* that responded, 40% were

living in some sort of supportive environment. Another 40% were home owners and 60% lived alone (See Figures 1a and 1b).

Does the consumer have a driver's license? (Q4)

Of the *general response*, 73.7% of respondents stated that the consumers in question held valid driver's licenses. All of the *consumers* indicated that they held valid driver's licenses. This question is an indicator of the level of performance of the consumer. It is assumed that those who hold valid driver's licenses function at a higher level in society than those who do not.

Does the consumer receive public financial assistance? (Q5, Q6, Q7, Q8)

Many consumers were living on limited incomes. Of the *general response*, over half (68.4%) of respondents stated that the consumer in question received some form of public financial assistance, 31.6% in the form of SSI and another 21.1% in SSDI benefits. At least 16% received support in the form of a housing allowance. Another 10.5% were unsure. They were utilizing Section 8 vouchers and Housing Authority funds.

There seemed to be some confusion over *consumers'* interpretation of the financial assistance questions. While only 20% of *consumers* indicated that they were recipients of public financial assistance, 40% stated that they received SSDI and another 20% stated that they received financial assistance from "Other" sources. Another 40% stated that they received some form of housing assistance. This assistance came in the form of Section 8 and an unnamed source.

How satisfied is the consumer with current housing? (Q10)

Only 26.3% of *general respondents* believed that their loved ones were "Very Satisfied" with current housing. This is contrasted with *consumer* reports indicating 60% as being "Very Satisfied" with their current housing.

What decisions influence choice of housing for consumer? (Q11)

As you can see from Figures 2a and 2b, *consumers* and *general respondents* agreed that the leading factor in their choice of current housing was "cost." All *consumers* and over half of *general respondents* made their housing decisions based on affordability. "Location" and "availability" were other leading considerations, while "level of care" and "subsidy" were of less importance in housing decisions.

Identified needs for new housing: Most important factors (Q12)

NAMI members were asked to select the top seven factors of most importance in choosing new housing. Their *general responses* are seen in Figure 3a. Helping services, such as Public Transportation, Medication Monitoring, and Money Management were ranked within the top three factors of most importance when providing housing for loved ones suffering from mental illness. The need for privacy, as reflected by Private Room was rated high on the list. Finally, the personal comforts items of Air-Conditioning, Smoking and living in a Pleasant Neighborhood finished in the top seven.

There were significant differences in opinions between consumers and NAMI supporters in their choices. While both groups agreed that living in a Pleasant Neighborhood, having Public Transportation, Private Room/Phones, and Air Conditioning are important, *consumers* placed Money Management or Medication Monitoring low on the list of importance. It appears safe to say that these *consumers* felt

they needed a lower level of care than did the loved ones of the general NAMI respondents. In place of those services, *consumers* want to be close to their families (see Figures 3b and 3c). Additionally, they targeted Activities, both Community and On-site, as being an important consideration. Privacy was an important factor. They cited, Privacy in Room, in Residence, and in Kitchen area close to the top of the list. Finally, *consumers* wanted the freedom to choose Non-Smoking units.

Insight into consumer preference in housing may be gained by examining the choices least chosen by consumers as factors in making housing decisions. The seven *general responses* least chosen were, in order of least importance: (Never chosen) Shared Room with a Private Storage Space, Laundry Service, On-site Medical Car, Emergency Help Buttons, or Involvement in Community Decisions. *Consumers* never chose Laundry Service, On-site Medical Care, Independence for Medication Monitoring, Independence from Money Management, Shopping Assistance, or Handicap Accessibility to be included in new housing decisions.

Support for Clustered Housing (Q13)

Participants were asked to respond to the question: If new housing for mental health consumers were built in your area, which of these options would you prefer? Preferences of *general respondents* and *consumers* are shown in Figures 4a and 4b. Of *general respondents,* the Multilevel Clustered Model was preferred over others with 68.4% of respondent making this choice. The Group Home and Clustered Single Family housing options were tied with 10.4% choosing them. Only 5.3% preferred No New Housing. Of *general respondents*, 79% supported some form of clustered housing. Likewise, most *consumers* embraced this model, with 60% endorsing some form of

clustered housing. All thought that new housing for consumers was needed. While no *consumer* favored New Group Home construction, 20% preferred Single Family new construction as the answer to future housing.

Discussion

Approximately half of represented consumers (either general respondent loved ones or self identified consumers) were already living in some sort of supportive environment and were receiving some form of public financial assistance, indicating that they were economically disadvantaged. Over 75% of all represented consumers had drivers' licenses, leaving 25% relying on public transportation to meet needs. While Availability of housing remained an important aspect for both parties, *consumers* considered Location in housing predominant over Cost.

The greatest disparity between consumers and general respondents came in choosing the most important factors for future housing. While all endorsed privacy and personal comfort items, *general respondents* chose the supportive services of Medication Monitoring and Money Management as crucial components in considering new housing for their loved ones, while *consumers* placed these items low on their list of priorities. It appears safe to say that these *consumers* felt they needed a lower level of care than did the loved ones of NAMI supporters. These *consumers* wanted to be involved in Community Activities and have the freedom to choose Non-smoking Units. Additionally, they want to be Close to Family. Examining these differences it could be argued that the *consumers* responding to this survey, by the very act of participating in NAMI, demonstrate self-determination and empowerment over mental health issues affect their

life. Keeping that in mind, 60% of these *consumers* endorsed some form of clustered housing. Similarly, g*eneral respondents* overwhelmingly supported this model (79%).

The findings support the theoretical frameworks of this study. By their responses, *consumers* indicated a need for a social support system. They want to live close to their families and be involved in community activities. At least 50% of this population is economical stressed. They need to feel a sense of control over the location (Pleasant Neighborhood) of housing, as well as over whether they have the right to smoke.

Study 2: Student Survey

Indiana University South Bend General Psychology students were surveyed to assess their knowledge and utilization of current housing and service options for consumers of mental health services in St. Joseph County. For this study, a consumer of mental health services is an individual who has been diagnosed with a DSM-IV mental illness or has been treated for a mental illness within the past five years.

Method

Participants

Participants in this study consisted of 51 introductory level general psychology students at Indiana University South Bend. The study was limited to students who: (1) are mental health service consumers, (2) have family members who are mental health service consumers, or (3) have close friends who are mental health service consumers. The consumer must have received services within the past five years from an agency that provides mental health services.

Materials

This study used the same research tool as Study 1 (see Appendix A: The *Consumer Satisfaction Survey: Assessment of Housing Needs of Mental Health Consumers in St Joseph County*).

Procedure

Students were notified of the availability of this study via an anouncement in class and an Invitation to Participate posting on a board in the student lounge in the Psychology department area of campus (see Appendix C for *Invitation to Participate*). Participation was voluntary. Participants who arrived for the study completed an informed consent form (Appendix D), which advised them of their right to withdraw from the study at any time without penalty. Students were informed that their answers would be kept confidential. Students were given research credits for their participation, which was used as a means of course and/or extra credit. Participants completed the questionnaires and placed them in a specially labeled box in the Psychology Department Lab office. They turned in a signed *Informed Consent Form* to a Psychology Lab assistant and received a *Debriefing Form* (Appendix E) and a credit receipt.

Results

The data were analyzed using the same techniques outlined in Study 1. Of the 51 students that completed the questionnaire, 30 identified themselves as female and 19 male. Approximately one fifth (N=10) of the group identified themselves as consumers of mental health services having a DSM-IV diagnosis within the past five years. The rest of the group either had family members or close friends that fell within this diagnosis. The

responses of individuals identifying themselves as consumers of mental health services (*consumers*) were compared to the rest of the respondents (*general responses*).

What is the consumer's current housing status? (Q2)

According to the students' *general responses*, at least 73% of consumers were living in some sort of supportive environment, either living with relatives, living in a Group Home, living as a resident of Portage Manor, homeless, or involved with the Supported Independent Living Program. Over half (51.2%) were living with relatives (see Figure 5). Comparatively, *consumers* responding to this survey were much more independent in their stated current housing status. Of these, 70% were renters. Another 20% owned their homes. Only 1 consumer, a male, said he was sharing a residence with a friend. This is what we would expect with this population of *consumers*, as they are functioning in society at the college level. It may be assumed that the population of consumers (who were most likely not college students) described by *general responses* required a more supportive housing environment.

Does the consumer receive public financial assistance? (Q5, Q6, Q7, Q8)

Many consumers were living on limited incomes. Of *general responses*, over a third (34.1%) of respondents stated that the consumer in question received some form of public financial assistance: 14.6% in the form of SSI and another 4.9% in SSDI benefits. At least 9.8% received support in the form of a housing allowance. Another 19.5% were unsure. At least 4.9% were receiving *Other* public funds. Up to 41% accepted some form of financial housing assistance. Identified sources of this assistance came in the form of Section 8 vouchers (4.9%) and Housing Authority funds (4.9%). It was clear in this

question that many *general respondents* were unsure how consumers paid for housing, as 29.3% marked *Don't Know* in response to this question.

Consumers' use of public funds (30%) was similar to the consumers described in the *general response* population. Only one consumer reported receiving housing assistance and this was in the form of Section 8. Of these public funds, 20% were in the form of SSI benefits.

How satisfied is the consumer with current housing? (Q10)

Both groups thought there was room for improvement in their current housing conditions. Only 26.8% of *general respondents* and 40% of *consumers* were *Very Satisfied* with current housing.

What decisions influence choice of housing for consumer? (Q11)

As you can see from Figures 6a and 6b, *general respondents* and *consumers* agreed on which factors were most important in influencing their current housing choices. *Cost* and *Location* were the most important considerations in this matter. While they agreed on the leading determinant factors, the degree of influence that individual factors weighed on their choices was very different. All *consumers* considered *Cost* in making the housing choice and 70% were swayed by *Location* of this housing. Very few of them considered the *Level of Care* or *Subsidy* option. By contrast, *general respondents* seemed to look at all the various options and make their decisions based on a combination of factors.

Does the consumer have a driver's license? (Q4)

This question was used as an indicator of the level of reliance on public services. As noted previously, it is assumed that those who do not hold a valid driver's license

have a greater need for public services. Questionnaire items, such as *Access to Public Transportation*, *Close Proximity to Transpo*, *Access to Community Activities*, and *Close Proximity to Shopping Areas* were included to assess this need. Less than half (48.8%) of *general respondents* stated that the consumers in question held valid driver's licenses. Assuming that all five of the consumers under age 18 were non-drivers, there were just over half (55.5%) of the remaining consumers who drove. All but one of student *consumers* indicated that they held valid driver's licenses. It is assumed that those who hold valid driver's licenses function at a higher level in society than those who do not.

The most important factors needed for future housing decisions. (Q12)

Students were asked to select the top seven factors they believed to be of most importance in making future housing decisions for mental health service consumers (see Figure 7a). Factors are listed in the order of most to least often selected. The percentage that each item was selected is marked alongside that item. For example, 53.7% of *general respondent* participants chose being in *Close Proximity to Family* as the most important consideration when choosing new housing. Support services, such as, *Money Management* and *Medication Monitoring* were ranked within the top four factors of most importance. Almost half of the *general respondents* (48.8%) acknowledge the consumers' need for privacy, as reflected by their choice of *Private Room* rated as third in importance. Needs of comfort and convenience, such as *Air Conditioning*, *Access to Public Transportation Systems*, and *Own Washer and Dryer* were also essential. Finally, *general respondents* were concerned about consumers' neighborhoods. *Pleasant Neighborhood* was selected (36.6%) as one of the top seven factors influencing future housing decisions.

Consumers' responses to this question differed sharply. Figure 7b shows that 60% of *consumers* valued *Air Conditioning*, a *Pleasant Neighborhood*, and a *Private Parking Area*. One half of participants wanted to live in their own *Private Residence* with a *Private Phone Line* and their *Own Washer and Dryer*. They wanted the freedom to have a P*et* and have a nice *Recreation Area* available to them.

Insight into consumer preference in housing may be gained by examining the choices least often selected by consumers as factors in making housing decisions. While both groups agreed that living in a *Pleasant Neighborhood* and having A*ir Conditioning* are important, *consumers* placed *Money Management* (30%) or *Medication Monitoring* (20%) low on their list of importance. In place of those services, *consumers* want privacy, as indicated by their selection of *Private Parking*, a *Private Phone* and to live in a *Private Residence* at the top of their priority list. Table 2 lists all remaining responses in order of importance to *general respondents* and *consumers* (see Table 2).

Support for Clustered Housing (Q13)

Participants asked to respond to the question: If new housing for mental health consumers were built in your area, which of these options would you prefer? Of *general respondents,* 68.4% of students supported some form of clustered housing. Support for clustered housing was even higher among *consumers with 80%* supporting some form of clustered housing.

The preferences of *general respondents* are shown in the Figure 8a. The *Multilevel Clustered Model* was preferred over others with 24.4% of respondent making this choice, followed by *Clustered Group Home* (22%). Only 2.4% preferred *No New Housing.* Likewise, most *consumers* embraced this model with 40% of those responding

to this question endorsing the *Multilevel Clustered Model. Clustered Housing* and *Clustered Group Home* each received another 20% of their endorsement. All thought that new housing for consumers was needed (see Figure 8b). While, *Single Family* new construction was preferred by 20% of *consumers,* no *consumers* favored new *Group Home* construction.

Discussion

The Clustered Housing Model was overwhelmingly endorsed by respondents with 80% of *consumers* and 68.4% of student *general respondents* supporting some form of clustered housing.

On first glance, the consumers in the student study appeared to be less dependent on public funds than NAMI consumers, with only 41% accepting some form of financial housing assistance. On closer examination, it is noted that approximately a third of respondents did not know the financial status of the consumer for whom they were responding. Only about a third, overall, were *Very Satisfied* with their current housing with *Cost* and *Location* identified as the most important considerations in this matter. *Location* served a doubly important role as only half of *general respondents* (55.5%) drove.

When identifying future housing needs, there were differences in opinions between *general responses* and *consumer* responses. Both groups agreed that living in a *Pleasant Neighborhood,* having *Air-conditioning,* and *Owning a Washer and Dryer* were at the top of the need list. Students, answering for loved ones, valued being in *Close Proximity to Family* and having the supportive services of *Money Management* and *Medication Monitoring.* While they acknowledged the need for privacy, they chose a

more supportive solution for their loved ones (*Private Room*). These supportive services were not among *consumers'* top priorities. They preferred items offering more privacy, such as a *Private Parking Area,* a *Private Phone Line,* and to live in a *Private Residence.* Finally, *consumers* valued having a *Recreation Area* and having a *Pet.*

As indicted by these results, consumers need to feel a sense of control over personal space. They need to be able to choose their neighborhood and want to take care of their own personal needs (O*wn a Washer and Dryer*). They need a social support system. While c*onsumers* look for support in a nearby R*ecreation Area, general respondents* rely on being in *Close Proximity to their Families.*

Study 3: Consumer Focus groups

In cooperation with the Center for the Homeless in South Bend, Indiana, and a local mental health service provider, Madison Center and Hospital, focus groups met to address housing needs of mental health consumers. The focus group format allowed for informational input regarding consumers' feelings about housing options, potential barriers to maintaining permanent housing, and preference for mental health services which may be attached to housing. This qualitative type of methodology allowed for a broader range of options to be explored and the intent of individual consumers to be clearly understood (Krueger, 1994).

Method

Participants

The interests and opinions of three separate groups were explored in a series of Focus Groups, which were conducted with eleven members in the first group, eight members in the second group, and four members in the third group.

Focus Group 1 (F1) consisted of 11 former residents of The Center for the Homeless who were acquainted with each other through the common bond of having been homeless. These participants were part of a Drop-in support group that meets weekly. It was a angry group, with racial/gender undertones spewn throughout the session. This group appeared to view their future housing options as very limited, as indicated by their voiced anger at the Government for the homelessness they had experienced.

Participants for the second group, Focus Group 2 (F2), were current residents of The Center for the Homeless who met weekly to address housing needs and barriers to obtaining permanent housing. There were eight participants in this group. Since this group was smaller than F1, it seemed that they were able to focus more directly on the specific issues. They seemed more optimistic about future housing options. Responses were given in an orderly manner and the members of the group seemed to weigh and give support to each other's opinions.

The third focus group was comprised of consumers diagnosed with severe mental illness as outlined in the DSM-IV manual. These consumers received outpatient services through a local mental health service provider. Four consumers participated in this study. The members of Focus Group 3 (F3) had varing degrees of active symptoms and were already living in housing situations where there were other consumers in the same building. Their housing ranged from 24 hr. nursing facility to group home and they readily addressed the advantages and disadvantages of congregate living. As this was a much smaller group than the other two, more individual time was given to each member to respond to the questions.

Materials

This study used the focus group design described by R. A. Krueger (Krueger, 1994). This method is a qualitative design that allows the voices of individual participants to be heard, while allowing immediate group feedback. Participants are free to change their minds and concensus is not required for the group to be successful. The group moderator focused on questions ranging from general knowledge of current housing options to specific needs to sustain permanent housing. These questions are contained in the *Focus Group Topic Guide* (see Appendix F). The results of these sessions are printed in "Content of Speech" in the Results section.

Additionally, the focus group members filled out the The *Consumer Satisfaction Survey: Assessment of Housing Needs of Mental Health Consumers in St Joseph County.* Results of this survey are in "Survey Analysis" in the Results section.

Procedure

Announcements of the study were given a week in advance by the support group leader at the Center for the Homeless for focus groups 1 and 2. Participants had the option of contacting the Center for the Homeless social service director or phoning the researcher directly to indicate interest. Participants in the Madison Center and Hospital focus group were selected by the researcher through screening with the Adult Day Treatment director.

Participants who arrived for the focus group meetings were advised of the nature of the study and informed of their participation rights. They completed an informed consent form (see Appendix G), which advised them of their right to withdraw from the group at any time. Participants were informed that their comments would be kept

confidential. Pizza was served during the first focus group meeting in an attempt to provide an informal atmosphere. Breakfast was served during the second focus group and the third group met at a local restaurant for dinner. Meals were determined by the time of day that the group met. The moderator asked a series of questions to assess housing and service needs aimed at sustaining permanent housing. Each participant was urged to contribute to the study. A research assistant was present to encourage conversation and provided feedback to participants' responses. The sessions were recorded and both the moderator and the assistant met at a later date to evaluate the format effectiveness of the meeting. An abridged transcript was prepared using the taped conversations. Emerging themes were categorized. Comparisons with the results from the other two studies in this research are found in the general discussion section.

Results

Survey Analysis

The data were entered into an SPSS 11.5 worksheet and analyzed to identify which mental health services are most valuable to focus group members. Participants filling out the survey questionnaire consisted of 12 males and 11 females. Of these, fifteen (62.2%) identified themselves as consumers of mental health services. Another two said they were "mothers of consumers" and four stated that they were a "close friend" of a consumer. The response "other" was selected three times. As in earlier studies, the responses of individuals identifying themselves as consumers of mental health services having a DSM-IV diagnosis within the past five years (*consumers*) were compared to the rest of the respondents (*general responses*).

What is the consumer's current housing status? (Q2). According to the *general responses* (those who did not identify themselves as mental health services consumers), 75% were *Renters*. One was living in a *Group Home* and one was H*omeless. Consumers* current housing status was much different. Over half of these participants were *Homeless* (53%). Only 20% of them were living independently, as *Renters*. None owned their homes. The rest were living in a supportive *SILP* environment or in a *Group Home* (see Figure 9).

Does the consumer receive public financial assistance? (Q5, Q6, Q7, Q8). Most *general respondents* in the focus groups reported that the consumers were receiving public funds. One participant was not sure, but 75% claimed the consumers were receiving public financial assistance in at least one area. Looking at Figure 10a, over a third were reported to be receiving supplemental income: 25% percent in the form of Federal disability checks. One fourth reported consumers received a *Housing Allowance.*

There seemed to be some confusion over *general respondents'* understanding of the financial assistance questions. While only 25% reported that consumers were recipients of a *Housing Allowance*, 50% responded with Y*es* to the question: Does consumer receive housing assistance? Another 25% were unsure of the answer to this question. Of the 50% of Housing Allowance funds received, half was in the form of *Housing Authority Subsidies* and the other in *Section 8 Grants*.

Most focus group *consumers* were receiving public funds. One participant was not sure, but 73.3% claimed to be receiving public financial assistance in at least one area. Examining Figure 10b, over half of the focus group *consumers* were receiving some form of State or Federal income supplements (*SSI* or *SSDI*). Figure 9b (Current Housing

Status: *Consumers*), showed that only 3 individuals were living independently, as *Renters*. Of these, two were receiving a *Housing Allowance*. It is an interesting fact that when *consumers* were further asked in Question 5: Does consumer receive financial housing assistance, 60% responded *Yes* to this question. It is assumed that the assistance that they are referring to, other than rent, is lodging at the Center for the Homeless, as over half reported that they currently reside there.

What decisions influence choice of housing for consumer? (Q11). As you can see from Figure 11, *consumers* and *general respondents* were in agreement with their opinions on the factors that influenced their current housing decisions. *Cost* was the leading deciding factor with *Location* and *Availability* other important considerations.

How satisfied is the consumer with current housing? (Q10). This survey indicated that consumers see the need for improvement in their housing options. While 75% of *general respondents* reported that the consumers were renters, they said only 25% were *Very Satisfied* with their current housing. *Consumers* were very disillusioned with current housing. Only 6.7% reported being *Very Satisfied* with current housing, while, 40% were *Very Dissatisfied* with the current situation. This is expected, as over 50% of this group reported being homeless.

Does the consumer have a driver's license? (Q4). This question was used an indicator of the level of reliance on public services. It is assumed that those who do not hold a valid driver's license have a greater need for public services. Questionnaire items, such as Access to Public Transportation, Close proximity to Transpo, Access to Community Activities, and Close Proximity to Shopping areas were included to assess this need. Of the *general respondents*, only half (50%) stated that the consumer held valid

driver's licenses. Less than half (46.7%) of *consumers* indicated that they held valid driver's licenses.

Identified needs for new housing—most important factors (Q12). Focus group participants were asked to select the top seven factors of most importance in choosing new housing. Their *general responses* are seen in Figure 12a. Having a *Private Phone* was rated as 1st on their list of priorities, with 62% of participants making this choice. *General respondents* were in agreement with each other on which items were most important to future housing. The next seven items all were selected 50% of the time. Consumers' need for reliable transportation was reflected in choices *Access to Public Transportation* and *Close Proximity to Transpo*. Participants want to live in a *Private Residence* with a *Security System*. They want the convenience of *Owning their Washer and Dryer* or at least have access to an *On-site Coin Laundry*. Finally, they want to be involved in *Community activities*. All remaining responses, with percentages chosen, are listed in Table 3.

By comparison, two- thirds of *consumers* picked *Air Conditioning* as the most important consideration in future housing decisions. *Consumers* agreed with *general respondents* that having their *Own Washer and Dryer* and a *Private Phone* were leading factors. While *general respondents* choices were divided evenly across the next seven items of importance, *consumer* agreement among each other was lower for the remainder of the responses. As with those participants giving *general responses,* being in C*lose Proximity to Transpo* and living in a *Private Residence* were in the top seven. Not selected by the *general respondents*, but of importance to *consumers,* were living in a *Pleasant Neighborhood* and being *Involved with Community Decisions*. Finally,

consumers want to be able to *Smoke* if they so desire. All remaining responses are listed in Table 3.

Insight into consumer preference in housing may be gained by examining the choices least chosen by consumers as factors in making housing decisions. While all items on the Consumer Satisfaction survey Question 12 were chosen to some degree by *general respondents, consumers,* on the other hand, had six items they never selected to include in new housing decisions. They did not want *On-site Case Management* or the services that a Case Manager might provide such as *Assistance with Grooming* or *Medication Monitoring*. They did not think that they needed *Emergency Help Buttons* and they did not want to *Share their Room* with another (see Table 3).

Support for Clustered Housing (Q12). Participants were asked to respond to the question: If new housing for mental health consumers were built in your area, which of these options would you prefer? Preferences of focus group participants are shown in Figure 13. *General respondents* preferred construction of more *Single Family* and *Apartment* dwellings to any type of clustered housing option. *Consumers* embraced the clustered housing model concept, with 80% of *consumers* choosing some form of clustered housing for new home construction. The *Multilevel Clustered* model was selected 46.7% of the time. Only one person from either group did not see the need for new housing construction for mental health consumers.

Content of Speech

What is the consumer's current housing status? Of the 23 participants in this study, 9 listed their current housing status as "homeless," even though only 8 participants were currently residents of the Center for the Homeless. Another 9 answered that they

were "renters", 3 were "residents of a group home", and 2 were involved in the "Supported Independent Living" (SILP) program. They were knowledgeable of alternate housing options and could name several of the ones listed in this research, as well as others not mentioned, because they did not meet the model of housing criteria for this study. For example, a male from F1 cited "the Y.W.C.A." as an option, while a female from that group disagreed stating that she believed it "is more of an activities thing." Other suggestions included the "Upper Room", "The New House", and the "Life Treatment Center" (Drug and alcohol rehab facilities). Humor was added to the seriousness of the issue of limited housing by the responses of: "the hole in the wall," "treehouses," "abandoned buildings," and "cardboard under a bridge," The observation was made that "there's a lot of people who are really homeless, but live with extended families."

When asked to describe the ideal house, one women (F1) expressed the belief that finding housing was subject to racial discrimination and addressed a white woman in the group, "You the right color, you know." The rest of the group reacted strongly, some agreeing with the women and others at variance, all yelling at once. What participants seemed to agree on was how "hard it is to find decent housing." Tom (F3), stated, "I'm in a bad spot because I'm in a nursing home. A lot of my fellow people living out there are in a worse state of mind than I am…a lot more elderly. I can't live on my own without some supervision. The only other alternative would be to get a solid roommate, someone with a good state of mind, that would share an apartment."

Most Important Considerations for Future Housing. The greatest advantage of the interview method of research is that it allows participants to voice their opinions without

the limitation of a having to select from a narrower range of choices that might be found on a questionnaire. The questionnaire is only as useful as the imagination of the author to second guess the most common responses and include them as choice options. Therefore, in scrutinizing the content of the focus sessions, several factors emerged of great importance to housing that were not able to be discerned from the questionnaire responses alone. Thus stated, there were several factors important in considering future housing that stood apart from the rest. The top seven responses in order of importance were: Privacy, Empowerment, Affordability, Individuality, Socialization, Location, and Security. Little mention was made of the individual amenities associated with the survey tool.

Privacy. Respondents most valued their sense of personal space or privacy. That is understandable, for as we examined the demographic section of the questionnaire we noticed that 39.1% of the respondents were currently homeless. The rest of the participants were in residential placements or lived in an apartment setting.

While the overall impression was that respondents needed personal space, their definitions of p*rivacy* varied. On one extreme was the man (F3) who was currently living in a nursing home and was satisfied simply in sharing his *space* with a "happy" roommate. He stated, "I found a big factor in living in a nursing home to be the quality of your roommate. I have a very good one now, but the fellow before him was just the opposite. This one is happy." At the other end of the spectrum was a woman living at the Center for the Homeless (F1), who wanted total *privacy.* She was apprehensive about sharing her *space* with others, stating that, "Some people do not want to be housed with other people. They want to have their own place. Something to strive for." Another

female (F2) concurred with this thinking, avowing, "Some people don't want to deal with other people's issues. They want to deal with just their own."

The other responses fell somewhere between these extremes. One young man (F3), living in a group-home, where he shares a room, wanted a place where he could play his music loud: "I'd kinda like to be independent too, more than I am. I like my music loud, I like to play my music loud." Along the same line, another man (F2) echoed these sentiments stating, "I have a hearing problem. I would want to turn the T.V. or radio as loud as I'd want it to, without someone banging on the walls." A woman (F2), who has lived in a group-home in the past and is now living in an apartment voiced that she enjoyed being free " to run around naked in the house" if she felt like it. Still another bemoaned, "I share a room and it's kinda not very good because I don't get very good sleep." One woman (F2) stated, "I lived at the Y for a period of time. And, we shared the refrigerators. I was very fortunate. I only had one other person in my refrigerator. I think that any of us want our own privacy, basically our own little self-entity of refrigerator, stove, you know, kitchen, bathroom, living room, bedroom, or if not necessarily a bedroom, at least a sleeping area within the living room, or something like this." Yet, another woman from this group retorted, "Some people could tolerate space that's shared by people like you. Other people would prefer having their own bedroom, living room, your own kitchen, your own bath, and have that much space."

While privacy was listed as the number one priority for housing, privacy did not necessarily mean isolation from others. One woman's (F3) need for companionship was expressed in her comments: "I really like having my own apartment, I love having my own apartment, but still sometimes it gets lonely. I go out to talk to people and there's

nobody out there, and I don't know if it's OK to go to their apartment and knock on the door 'cause I don't want to bother them. If we had a place to go and play cards and exercise and games, then people would know about that room and be able to go down there, 'cause they could be lonely in their apartments too." Another (F2) worried about the safety of being too independent. She recollected, "There's been a couple of times we had the paramedics out. Other people have come to our complex and knocked on the door and said 'if you ever need any help, call us.' So, I mean, it's like another add-mix. Yes, a certain amount of privacy, but someplace where, you know, if you need to knock on someone's door in a hurry, you can." According to one of the participants of the Center for the Homeless focus group (F2), who had graduated into her own housing and now assists the Center with placements, "twenty percent of the people that we discharge into housing, we make sure that they are eating everyday. We are going to their homes and someone will have them come out of their rooms to eat, because you know that they won't cook for themselves. Then we've got sixty percent who are independent. Want their own room. Want their privacy. Want that, and are capable of that, and have demonstrated that capability."

Empowerment. Consumers need to feel a sense of empowerment in housing issues. From the color of the walls to the location of the house, participants were adamant that their choices be heard. Consumers would like to be able to choose the type and location of their housing. According to a respondent (F2) living at the Center for the Homeless "it is wonderful that they have public housing. I just don't like the fact that you know that it is a public housing by the way it looks." Her choice would be "a regular house, but owned by public housing and have it look like it blends in with the

neighborhood." Another woman from this group agreed, stating, "Peoples' trash cans are exactly the same. They all have the same look that says Housing Authority on it. The concept is good, just everything is identical, right down to the color." And speaking of color, the choice to decorate to reflect personal taste was mentioned often and is addressed further in the section on Personality. One woman (F3) protested that in most public housing "the walls are drab, like dull beige, not happy." She stated, "It would be nice to say this is my place and I decorated it the way I wanted."

While some consumers bemoaned the public housing option, others chose a less critical outlook. One person (F2) noted, "They have waiting lists that are years long. People are trying to get there. I heard one person say 'If I go to live there, they will know I am low income.' Nooo. People are going there because it is affordable. A lot of them are safe. I think that is kinda the stigma of the past, and living in South Bend is so nice."

Several consumers (F2) mentioned the need to live in an area that has convenient access to metropolitan areas "where they could catch the bus, right there. They could walk to the store, to the Laundromat. Everything is right there." As one woman (F2) put it, "I know people here, that just didn't want to be in a house, they wanted to be closer to town, to a Laundromat, so they went right there, where they could walk down the street to a Laundromat. They didn't care if they lived in a string of houses." Given that less than half of the participants had drivers' licenses it makes sense that this factor was listed as important in determining housing preference.

Of great concern to consumers was control over their limited monies. One male participant (F3) feared that he would "have to sign an agreement for X number of years"

or "sign my social security receipts to a facility." Others (F3) worried about what would happen to their housing if they were "not able to work."

Consumers want to feel a sense of permanence in housing. One woman (F3) expressed her frustration with temporary housing, saying, "When you live in an apartment, and rent, then you can't do nothing, the landlord wants it his way. Then this isn't a home, it's just a place to live." Another drawback to renting is restriction of pet ownership. One renter (F3) lamented, "We can't have pets. I think it's important. It helps you from not getting lonely so much."

Again, this population of consumers may be used to having others make housing choices for them. That does not mean that they are content with the way things have been in the past. This feeling might best be expressed by one man's (F1) frustrated comment, "What choices?.... Come on, man." They (F3) want to "live where *they* want, find things to do, and not have to live under somebody's rules." As one consumer (F3) put it, "That's nice because a lot of times it is not good to live under somebody's rules and not have your mind." Perhaps one consumer (F2) said it best. "It is all in choices. It comes down to whether I'm capable of choosing, and if it's tailored for me."

Affordability. As mentioned previously, consumers are very concerned about how their incomes are managed and how affordable the different housing options are to them. Over 73% of respondents receive public funds. Many of them live on fixed incomes. Over a third of them are homeless.

Respondents seemed divided on their feelings about accepting housing assistance based on income. One male participant (F1) noted, "If they got their Social Security, whatever, and they want their rent based upon their income, you know, if your income's

not going to go up, your income's not going to go up, and you're a set person, then it should stay set. Some people need a house and their income's not going to go up, they're not going to keep growing." Others (F3) feared entering "an agreement that you would sign your social security receipts to a facility for X number of years" for rent.

One consumer (F1) suggested that it "would be helpful, if they would have some kind of a housing to help people out that are just starting out. If you are struggling a little bit, your income might be low, but I don't think they should keep your rent low, as you move up. You know? You need to pay for what you have." Another woman from this same group believed that "If someone can't pay for it, I think they should live there for nothing." Not all agreed with this thinking. One women (F1) voiced concern that "If you kept it real low, it might get abused."

One man (F1) suggested that instead of renting a place, consumers should have the option to purchase a home. He stated that he wanted to find a place that was "worn down and then I want… ah… loan breaks or interest free loans and the ability to be able to work on it myself. That ways it's more mine." Most of the group agreed with him that they would like to see monies available to purchase their own homes. A Center for the Homeless resident (F1) stated that she wanted to "see a program that uses a home that need to be improved, but that gives you the money to improve it."

Another woman (F1) lamented, "It is not right for a single person to buy a house. Its hard for 'em." She continued, "When you have kids you never own anything. You don't have anything to call your own." Her dream would be to see a program where "once they see that you was responsible. Then you know, you go in and start buying a home. Instead of going through all the pain of waiting three, four, two or three years to

get your house built from the ground up. Actually you will get it in hours instead, if not days."

One gentleman (F3) pointed out that many people do not know their options when they apply for aid. He stated, "There's the housing assistance office, that's where people could really go instead of subsidized housing. I think that would be better if people knew that they could do that."

Individuality. Of much interest to this study, in the light of the objective of the Olmstead Act, which is to give consumers the right to be integrated into and become a viable part of the communities in which they live, is the desire of the consumer to establish his/her own personality in regard to housing. One woman (F3) felt it "important that you decorate where you live in your way to make it homey." Another (F3) agreed, declaring, "I think when you decorate your own place and choose your own carpet then that is your home." One woman (F3) made the best out of her rental situation and stated, "Wherever they put you, you can decorate yourself. You do the best you can. I do the best I can at decorating my apartment." Still another (F1) thought that "if the potential's there that I can work and do a little this, that, and the other to bring it up… I'm not talkin' bout droppin' a whole lotta money. I'm talkin' about ….you know…maybe aesthetics." Another woman (F3) was adamant in declaring, "I wanna have the freedom of making it look like whatever I want it to." Another woman (F3), drawing from her personal experience of living in subsidized housing mourned, "You have to live in the drab and dreary colors that they pick for you. And that makes you lonely too." One woman (F2), still homeless, yearning for her own place, spoke softly. "It would be nice to say this is my place and I decorated it the way I wanted. I did all this."

While some consumers were affronted by the thought of having to live in public housing, others (F2) noted that many houses that are built today are in "subdivisions" and "they all look alike." They seemed to take comfort in the fact that "poor rich people have opted for the subdivision choice" and that those people are, also, "limited as to design and color." Several respondents (F1) wished that they could have "a nice yard…front and back with a fence," at which several of the group members burst into singing a moving rendition of "*Tie a yellow ribbon 'round the old oak tree.*"

For others (F1) it was important that they establish their own residential identity. For example, one young man remarked, "Some people do not want to be housed with other people. They want to have their own place."

Socialization. While we mentioned earlier that consumers value privacy, we also acknowledge that consumers needed companionship. This concept is essential to the integration model of the Olmstead Act and it was heartening to see that consumers identified the need for socialization as one of their top seven housing priorities. Consumers need one another to feel safe, to avert loneliness, to feel understood, and to feel a sense of belonging.

While consumers value their privacy, they want to live close enough to others to feel safe. One woman (F2) reported, "There's been a couple of times we had the paramedics out and people came. Other people have come to our complex and knocked on the door and said 'if you ever need any help, call us.' So, I mean, it's like another add-mix. Yes, a certain amount of privacy but someplace where, you know, if you need to knock on someone's door in a hurry, you can." A man from her group agreed, recounting the time that "my great aunt that had a stroke, and was on the floor for about four hours

before she was found." Another man (F2) suggested using "some kind of monitors inside the apartments, or something. You push a button, or… I know…some apartments have bells or intercoms. You can push a button and it goes right to the police station." Another women (F2), resolution in her voice, stated: "It's all about people being able to render assistance to each other." She recounted the time when she "was in an apartment complex in St. Joe, Michigan, where most of the bottom floor was elderly. And they were all running around each other, helping each other a great deal. One gal was in a wheel chair, so the people would drop in to see how she was, and make sure everything was correct." She stated that this is different from most neighborhoods where, "It can be very distanced in this country. People are often very distant from each other, unless they know each other for years. They just get very afraid."

While earlier we examined consumers' need for space, personal space must be weighed against the (F2) "need to be close to other people." For example, Sharon (F3) pointed out, "I really like having my own apartment but still sometimes it gets lonely. I go out to talk to people and there's nobody out there, and I don't know if it's OK to go to their apartment and knock on the door 'cause I don't want to bother them. If we had a place to go and play cards and exercise and games, then people would know about that room and be able to go down there 'cause they could be lonely in their apartments too." Others (F2) embraced this "community room" concept "where we all could come together." Sharon (F3) stated, "When you live single in an apartment you get bored at times because there's nothing to do." One woman (F2), currently living in "an apartment complex," stated that they "have a community room. And, on the average of about once a month there is a something that the complex puts on. And, I mean, you know, its like

anything else, you have the option to attend or not. People can mix. Get to know other people. You might realize that you both have the same problems." Along with companionship, Tom (F3) would like to see "a modern recreation room." Others agreed. Sharon (F3) thought that it would be "helpful" to "have some exercise machines in there, a tape player, a table for cards. We would get together more, it would help a lot more." This seems to support the survey results where 26.1% of respondents chose recreation as an important consideration in housing.

While some consumers focused on having a community room within their housing complex, others sought companionship in their neighborhood. Matt (F3) wanted to live "closer to downtown because there are a lot of people that don't have things to do that I can make friends with. I never got bored."

Consumers need to feel understood. They need to know that there are other consumers nearby, who understand their mental health issues. Furthermore, they need to feel like they can count on each other for help. As one woman (F2) observed, "You know, you may find two people…and I'm not talking about, like, boyfriend girlfriend type thing, but two people who suddenly become friends, and kinda keep track of each other." Another added to the conversation, "you might realize that you both have the same problem, and its, you know, and there are different stages of mental illness, obviously." One male summed it up with, "And people with mental health problems, they can change rapidly. Certain people can change if they don't take their medication. In some cases, people being around notice the changes. It does help." The first woman agreed: "You know, they may live on opposite sides of the complex, or wherever, but, you know, if nothing else, they pick up a phone and call, or say, 'Hey, you doing OK', or

let's check in with each other, every other day or something, so that you do develop friendships, whether…. you know, you don't necessarily go out of your way, but, you know they're there."

Finally, consumers need to feel a sense of belonging in the community. One woman (F3) summed up this longing in her statement. "I do like group home living because it's like a family. You get to plan parties for everyone. I used to do that and I had a lot of fun. Like at Christmas time buying presents for everyone, made me feel good inside."

Location. Consumers are concerned about where their housing is located. By *location* some referred to the pleasantness of the neighborhood while others were more concerned that they be conveniently close to bus lines, shopping areas, or Laundromats. According to the survey tool, over half of the participants did not have a driver's license, so it makes sense that consumers need to be close to a public transportation source or to a metropolitan area. One male (F2) stated that "location" was his most important consideration in housing "because I ride the bus. That is the only way I can get around and I cannot walk that far, so a bus has to be top priority." One woman (F2) differed slightly in her view, stating she found it "more important to be near things you can walk to rather than close to a bus, because the bus lines, the way they run, when you go shopping, it takes as long as three hours, and that's not including the shopping." Another woman (F2) agreed with the first, stating she "wanted to be closer to town where she could walk down the street to a Laundromat or a grocery store, so that you could get your basic needs met." The first man acknowledged that, "Both of them are important. You need a mix of both, really." Convenience played a factor in one man's choice of

housing location. He wanted to be "closer to downtown because there are a lot of people that I can make friends with. I never got bored."

In the survey tool 34.8% of respondents selected P*leasant Neighborhood* as being one of the top seven most important items to include in future housing decisions. Members of the focus group supported that finding. They feel a need to live in pleasant surroundings. Furthermore, as one woman (F1) expressed "I want to pick out the neighborhood I want to live in, too." There seemed to be some dispute about whether urban or rural living is preferred. One male (F1) wanted the option to "pick a house, like maybe, on an acre." Another male voice (F1) chimed "two acres." The first declared, "Not everybody wants to live in a neighborhood." Another woman (F1) strongly disagreed, "It's good for you thinking like that, but in a situation like me, having three boys, I got to stay on the home front. I got to stay in town. I got to stay around for the schooling areas, you know." She further contended, "Working the hours that I do, it would be too hard for me to live on one acre with my neighbors two miles down the road. Boys out there by themselves, you know." Other responses offered a compromise. Tom (F3) just wanted "a nice lawn." Another woman (F1) hoped for enough space "to put in a garden." Most agreed, "There should be options."

All agreed on what they did not want. They did not want to live in housing "where you are so close you can reach out and borrow a cup of sugar without even leaving home" (F1) or in an unsafe neighborhood where you might find "drug addicts." (F1).

A majority of participants in this study were living in public housing or were homeless. Thus, it is interesting to hear their thoughts regarding their preference of public

versus private housing. One woman (F2) bemoaned, "I think it is wonderful that they have public housing. I just don't like the fact that you know that it is public housing by the way it looks." Another woman agreed, wishing that it could "just be a regular house, but owned by public housing. And have it look like it blends in with the neighborhood. They all have the same look that says Housing Authority on it." Perhaps the most insightful comment came from a woman (F1) who informed, "You are not going to please everyone. When we think about the housing that has been in our communities for years now. I mean public housing or low income. They have waiting lists that are years long. People are trying to get there. People are going there because it is affordable. A lot of them are safe." One man (F1), currently living in the Center for the Homeless expressed his frustration over his perception of inequality in housing locale. He stated, "People should be able to feel relaxed in their neighborhood, because, you know, they payin' the police's fare. And, you know, payin' the government and the mayor, and all that. So they feel that their neighborhood should be the best. Ya know, they's paying the big bucks. The little man is in another neighborhood. Like, he's like caught in between a rock and a hard place 'cause he wanna get what they have. He just like me, ya know." Another woman (F1) suggested, "That's where modeling comes in. Like you go a find certain people that will move in. Like, in Chicago they's got police movin' into the bad neighborhoods. You know, you got a police man as your neighbor…. you feel a little safer." "Ya," another woman replied. "You got this person who goes and sees this computer person got a big job and he's decided I wanna go and make a big difference here, too. Then you got this welfare family or whatever… and once she keeps seeing that this one over here got this house lookin' like this and her house … well man, his grass

look even prettier. You know, she gonna go get some green up stuff and put it all over." A male interrupted with, "Ya, she gonna look at 'em. They's got 'em a lexus…" (laughter) and a woman joined in with, "Ooh. Look at that car. He got two cars and I ain't got one. Then they ain't gonna want to settle. You found out he went to school. You gonna decide that you wanna go to school. What ya call it, uh…..like when you're next to somebody and whatever they throw off you catch?" The man answered with, "Emulate." The woman continued, "Ya right, emulate. OK. So that's what I'm saying. You got all these peoples mixed up together. They gonna see something better in the next person." One man (F1), beset with fear replied, "You don't know what you're sayin'. You're saying … you get these peoples comin' from Niles and Chicago… How would ya know them? You crazy doin' this. You talkin' about going to their level in their neighborhood."

Security. Consumers need to feel that their housing is secure. Consumers are financially and emotionally invested in their homes. They need to feel that what "you put into it over the years is what you can get out… and it can't be taken away"(F1). Consumers (F1) worry that if they get sick or "get hurt out on the job and miss a month's payment or something" they will be "threatened to lose it." One man (F1) proposed having an "assistance bracket" where "if you're out of work or something happens, you get it taken care of…and then get back to work and you don't lose it." Another man (F1) presented his theory that the government should fund "1st time ownership" for consumers, so that "what you put into that home you can't lose." Another man (F1) agreed, but expanded it to include ownership of apartment contracts. He wondered if, "Maybe you could own an apartment. Maybe a program can be worked out that once you

get into an apartment, nobody could throw you out." Others agreed, "Ya. Like a condominium."

Finally, consumers need to "combat the cycle of homelessness" (F1). The severely mentally ill are challenged in many areas that directly or indirectly affect housing. Many have fixed incomes and face long lists while awaiting openings for a limited amount of low income housing space. Some have symptoms, which may interfere with job stability. Others face large medical fees to cover medications. Over half of the participants of this study were currently homeless. One woman (F1) addressing her cycle of the homelessness dilemma stated, "I went through all the programs and everything I was suppose to do. Saved up my money and did all that and when I moved outta here, the Shelter for the Homeless placed me in an apartment that was simply breathtaking. I mean I had a view of the river. I had a room… Shopping right here. Everything. The park… Everything was right there. But after a year was up, my rent went up to $600.00 a month and you know what I did?…" Another women (F1) cut in, "You had to move." The first woman continued, "Uh hmm…You hear what I'm sayin.' $600.00 a month! They want me to pay $600.00 a month but there's a lady on this floor who's only payin' $25.00 or $30.00. She's on Section 8 with 7 children. She got so many kids, they make her get an apartment in both buildin's." (laughter). Another women (F1) offered, "The cycle of homelessness is what we're are all talking about. It's stopping that cycle. Because somebody doesn't have our back when something comes up, you lose your apartment and kids see grownups out there strugglin' and you know it's just a pipe dream. But it shouldn't be a pipe dream."

Perhaps one man (F1) summed up the whole security issue. "There's changes to be initiated in a lot of different areas to make it easier for people to become those first time home owners and to answer 'How are people going to be allowed to still go through hard times, or whatever, or four kids and one working parent, you know, and accomplish that without falling to pieces?' There has to be some leniency to back off the wolves. You know, when they came out of WWII their houses were worth eight times more than they were when they bought them. But there's not gonna be nothin' set up for people in our age bracket that ever prospers us that much. Not that I see now, unless, the system changes."

The Clustered Housing Model.

Advantages. Focus group members were asked to suggest possible advantages and disadvantages to living in clustered housing. Several participants in this study were living in consumer group-homes or were being assisted by SILP. When asked to respond to the question: *Do you feel comfortable living with other consumers,* their responses were mostly positive. They agreed that they felt safer and more comfortable living around people who understand their problems. Sharon (F3) shared, "Yah, I think that's really important. When people live in a community, consumers are important. Not everybody is the same and we've all got mental problems and if we all talked…like… 'My problem's not as bad as your problem' or 'Oh gee, I thought mine was bad.' We could interact with each other." Another (F2) responded with, "I think you need to be close to other people and render assistance to each other. People with mental health problems, they can change rapidly. Certain people can change if they don't take their medication. In some cases, people being around to notice the changes does help."

One woman (F2) embraced this model stating that the goal of the Center for the Homeless "is to get people to care for themselves or care for themselves under supervision, in which case, someone lives within the house versus the group home model, which is more independent." She stated that for "twenty percent of the people that we discharge into housing, we make sure that they are eating everyday because you know that they wouldn't cook for themselves. So they would go there." Advocating for the multilevel clustered arrangement she further informed, "We've got sixty percent who are independent. Want their own room. Want their privacy. Want that, and are capable of that, and have demonstrated that capability. So they would go into the next level. So that I definitely am agreeing that levels are needed." Another (F2), also, supported the multilevel clustered model stating that she "envisioned something, where depending on your needs, there is a certain amount of care that you get. I mean if it comes down to it, *there would be* community dining if you want it and you don't even have to cook if you don't want to." One woman (F2), further expanding on the level of care design, advocated for medical "monitoring for certain people that may need monitored because of their age or their mental health." Another (F1) agreed, stating, "Some people need a little help. They don't need to go to a nursing home *but* it might be helpful to have like an overseer so some people could live by themselves. It would be nice to have someone checking in on them and they need to feel good about themselves."

Others, when prompted to name the strengths of a clustered model, offered suggestions that ranged from being able to "understand the needs of the other" (F2) to alleviating "loneliness" (F3) to "feeling safer" (F3). For example, Sharon (F3), addressing loneliness, stated that she had lived in "a group-home, a halfway house, and

Supported Independent Program (SILP) housing." She is currently living in an apartment alone. She believed that "the best was group living, but I'm learning independent living and I'm liking it more and more as I go along." She embraced "group-home living because it's like a family." She thought that overcoming "loneliness" was the greatest obstacle to increased independence in living. In her own words, she questioned: "If there's nothing on TV what do you do? Do you smoke a lot? Do you pace back and forth? What do you do with yourself? That's the hard part that I have trouble with, the loneliness." Tom (F3) agreed offering, "I know that after my mother died I was left alone. I was working at the time, but you get home and there's nobody there. And all you can do is sit there and watch TV or read the whole night in a silent house." One woman (F2) offered the clustered housing option as a solution that could alleviate the loneliness factor. She proposed that even if consumers "may live on opposite sides of the complex, or wherever, they *could* pick up a phone and call to say, 'Hey, you doing OK', or let's check in with each other, every other day or something, so that you develop friendships." Others (F2) supported having "a community center where people can get to know other people and might realize that you both have the same problem." Sharon (F3) suggested that within that "community center-type of thing there *could* be different classes that would help us think of illness in a different way."

The multilevel clustered housing model allows for a variety of housing options within the same complex. For example, there might be individual apartment units, family units, or a higher care monitored facility all grouped within walking distance of each other. Consumers would have the option to reside in a unit based on their level of care need. Throughout the sessions the right to "privacy" was listed as a major concern to

consumers. While consumers value some sense of privacy, their definition of privacy varied. One women (F2) pointed out that a "mix" of options "would be good, because some people could tolerate" living in close quarters with other consumers and others "simply might not like being cramped into a situation where there are say, three or four persons sharing the same living room." Another women's definition of privacy was "basically our own little self-entity of refrigerator, stove, you know, kitchen, bathroom, living room, bedroom, or if not necessarily a bedroom, at least a sleeping area within the living room, or something like this." Still another (F2) supported the model but would want to have her own "personal apartment" within the complex where she could get away from "a certain kind of person you don't get along with." She, also, wanted to have the freedom to come and go. To "have the option of being there, so you are not forced to be in the situation all day or certain hours of the day."

One man (F2) like the idea that "all of the buildings would be centered around and convenient to grocery stores, laundry services, and stuff." Another woman (F2) supported this thought saying, "they could catch the bus, right there, they could walk to the store, to the Laundromat. Everything is right there."

One woman (F3) stated that she would welcome living in a community that has "kids running around." She insisted that "there are consumers that have kids, and we shouldn't have to be separated from them. A single person without kids shouldn't have to live in an apartment building with other people that don't have kids. Kids don't bother everybody."

Not one respondent indicated any discomfort with living with other consumers, in particular, but some listed dissatisfaction with other residential issues. For example, one

woman (F3), who was living alone in her apartment, lamented the fact that "We don't even talk. We need to have something like a program. Something that includes everybody in the building, not just something where this person feels like talking. There are a lot of times that I stay in my apartment 'cause there's nothing to do. At night I sometimes I get so bored that I eat, I do stuff that isn't healthy." Another man (F3) complained that he'd "kinda like to be independent too, more than I am. I like my music loud, I like to play my music loud. I share a room and it's kinda not very good because I don't get very good sleep."

Disadvantages. One woman (F1) thought that "its hard for kids to be around a lot of people that are depressed." A woman from a different focus group (F2) concurred. "Um, if you get a bunch of manic-depressives together, it gets kinda depressing." Another man (F1) echoed her thoughts, stating, "Cause when you get a whole bunch of people that live in one area and they are not working, it just brings it down, 'cause you have too much idle time." He continued: "In a situation like that, I don't see the mentally ill being helped 'cause I am constant seeing them and I'm thinking they are saying 'Woo-ooo-ooo-ooo I'm needin' to be out of here.' They are never going to be able to get out on their own. I think bein' around somebody that is down brings you down. It's not their fault. It's just how it is." He cited the Chicago projects as an example. "Like in Chicago, they was doin' the tearin' down of the projects and they decided that they was going to take these people that was from the projects and put them in different areas. A female from the group chimed in: "But they didn't really take them out of it. They took them out of big tall buildings but they put them back in with *the same* people that was low income."

Consumers need to feel a sense of control over the decisions affecting their housing. Matt (F3) worried that if he lived in a clustered housing setting he would have to "do what they like." He maintained that, "the better control you have over your life the better." Another (F2) agreed stating, "some people don't like to be given directions." One man stated that the "ability of choice makes you feel like a free person." Yet another was apprehensive of the model pointing out that "a lot of people don't like to feel that their independence has been stripped even if it has been curtailed, they don't want to feel like it's all gone."

Consumers need to feel security in their choice of housing. One woman reasoned, "why would I want to make payments on something that I would never own?" Consumers need to feel that they have choices in deciding the housing that is right for them. While Clustered Housing may offer another choice to those already available, one male consumer (F2) pointed out, "given the situation facing paying rent in this area" if someone had a serious mental illness, they might have to live in a community like that because "they really don't have much else choice out there, unless they want to pay very large bucks."

Finally, one man seemed to have a foreboding about the Clustered Housing option that he could not quite name. He cautioned, "I'm not sure about clustered housing, you know. Even the scripture says ' Woe to those who live house upon house'…you know. I mean if you just crowd people together you're not happy with the environment and I just don't think that the way the human cycle is…to be comfortable in that condition."

General Discussion

The focus of this study was to find commonalities of needs affecting housing that are specific to individuals suffering from chronic mental illness. In an attempt to hear all consumer voices regarding housing needs, this study utilized a diverse range of a study methods and consumer populations. Additionally, this study examined current National housing options for mental health service consumers and compared them with local need and housing availability. Finally, this study examined findings in the light of current theoretical frameworks. By examining the results, a comprehensive picture of housing need emerged for consumers. Fortunately, this study used both qualitative and quantitative research methods. While, consumers in both studies endorsed the clustered housing model, the quantitative study was limited by the forced choice response method. Issues of great importance to consumers were uncovered by the interview method that could only be hinted at in the survey analysis. Encouragingly, the results of this study provide impetus for designing a consumer-driven model of housing for our community.

As the data from the current study indicate, overall, *consumers* endorsed the Clustered Housing Model, with 87% supporting some form of clustered housing. Only 27% were *Very Satisfied* with their current housing status. Half were currently living in a supportive environment. In addition, another half were receiving public funds in the form of housing allowances, food stamps, SSI, SSDI, or homeless vouchers. Forty percent stated that they currently relied on housing assistance to maintain housing. *Consumers* stated that the major factors in selecting current housing were cost (80%), location (57%), and availability (47%).

Overall *general respondents* also endorsed the Clustered Housing Model with 66% supporting some form of clustered housing. As with *consumers*, only 27% of *general respondents* thought that the consumers they were representing were *Very Satisfied* with their current housing status.

Considerations for Future Housing: Expressed Need

Overall *consumers* surveyed selected "air conditioning" as the most important consideration in future housing. More than half of *consumers* believe that the location of future housing is of utmost importance and selected "pleasant neighborhood" at the top of the list. Half chose convenience items, such as, "owning a washer and dryer" and having a "private phone line." Thus, features such as comfort, location, and privacy were of importance to these consumers regarding their housing.

Overall *general respondents* viewed consumer housing quite differently than did *consumers* themselves. The top two items of most importance to *general respondents*, when considering future housing for their loved ones, were "money management" and "medication monitoring." These items came before the comfort items of "air conditioning", "owning a washer and dryer", or living in a "pleasant neighborhood." Additionally, they thought that their loved ones should live "close to family." Privacy was valued, but while *consumers* chose to live in a "private residence," *general respondents* selected "private room" for loved ones. The two consumer populations (the *general respondent* loved ones versus *consumers* actually filling out the survey) appear to differ in their perception of the level of supportive services needed to reinforce a sense of community integration.

While there were differences within the groups, certain commonalities of expressed need arose. For the convenience of this study, separate items in the questionnaire have been grouped into categories identified by focus group participants: Privacy, Empowerment, Affordability, Individuality, Socialization, Location, and Security. Additionally, survey participants identified one other category of need, which has been labeled here as Comfort and Convenience.

Location. Consumers are concerned about where their housing is located. Over half of survey respondents selected *Location* in response to Question 11: What decisions influenced choice of housing for consumers? By *location* some referred to the pleasantness of the neighborhood while others were more concerned that they be conveniently close to bus lines, shopping areas, or Laundromats. For NAMI *consumers*, their greatest need (80%) was to live in a *Pleasant Neighborhood*. Sixty percent of student *consumers* agreed, as well as 47% of focus group *consumers,* 37% of student *general respondents*, and 37% of NAMI supporters. Members of the focus groups supported that finding.

According to the survey tool, 39% of the participants did not have a driver's license, so it makes sense that consumers need to be close to a public transportation source or to a metropolitan area. Understandably, *Access to Public Transportation* made the top-seven list in importance for future housing locale for NAMI *consumers* and student and focus group *general respondents.* Others needed to be *Close to Transpo* (40% of NAMI *consumers*, 50% of focus group *general respondents,* and 47% of focus group *consumers*). One male in a focus group stated that location was his most important

consideration in housing "because I ride the bus. That is the only way I can get around and I cannot walk that far, so a bus has to be top priority."

With regard to empowering consumer preference, consumers want to have choices when picking out their neighborhoods that accommodate for their level of services needed, yet are aesthetically pleasing.

Comfort and Convenience. Consumers need the comfort items that most of us take for granted. *Air-conditioning* was included in the questionnaire to gauge the value of personal comfort items to consider for future housing. All groups valued this commodity and focus group *consumers* selected this item as their first priority in looking for new housing (67%). NAMI and student *consumers* and *general respondents* agreed, placing this item in the top seven of importance.

Additionally, consumers need the convenience of having their *Own Washer and Dryer* or having one nearby, such as an *On-site Coin Laundry,* as might be found in an apartment complex. Student and focus group *consumers* and *general respondents* placed this item in the top seven of importance to include in their future housing decisions.

Privacy. Consumers value their privacy. This need was expressed repeatedly, with 50% of student *consumers* and focus group *general respondents*, 40% of NAMI *consumers,* and 33% of focus group *consumers* stating that they preferred to live in a *Private Residence*. An equal proportion of NAMI *consumers* and student *general respondents* (49%) would be satisfied with just having a *Private Room*. All groups valued the discretion of having a *Private Phone Line*. Sixty-three percent of focus group general respondents, 60% of NAMI consumers, 50% of student consumers, and 47% of focus group consumers selected this choice. Perhaps one focus group participant expressed this

need best in her statement, "I think that any of us want our own privacy, basically our own little self-entity of refrigerator, stove, you know, kitchen, bathroom, living room, bedroom, or if not necessarily a bedroom, at least a sleeping area within the living room, or something like this."

Socialization. While we mentioned earlier that consumers value their privacy, we also acknowledged that consumers needed companionship and to find a sense of community. This concept is essential to the integration model of the Olmstead Act and it was heartening to see that consumers identified the need for socialization as one of their top seven in housing priorities. Consumers need one another to feel safe, to avert loneliness, to feel understood, and to feel a sense of belonging. As one focus group member commented, she needed to live in a place where she had "a certain amount of privacy but someplace where, if you need to knock on someone's door in a hurry, you can."

Student *general respondents* listed being *Close to Family* as the first priority when considering new housing. NAMI c*onsumers* agreed, with 60% making this choice. The questionnaire listed three types of social activities that consumers might choose to be involved in depending on their level of independence and need. While focus group *general respondents* expressed the need to be involved in *Community Activities*, NAMI *consumers* valued involvement in *On-site Activities*. Student *consumers* desired having a *Recreation Area* available to them.

While focus group participants stated that they valued their privacy, they want to live close enough to others to feel safe. One woman stated, "It's all about people being able to render assistance to each other." Other consumers opted for the choice to have a

Security System included in future housing decisions. Half of focus group *general respondents* chose this route to safety, supporting the focus group participant's suggestion of using "some kind of monitors inside the apartments, or something. You can push a button and it goes right to the police station."

Empowerment. Consumers need to feel a sense of influence in housing issues. From the color of the walls to the location of the house, participants were adamant that their choices be heard. NAMI *consumers* (40%) wanted to be able to choose *Non-smoking Unit*, while NAMI *general respondents* (37%) and focus group *consumers* (33%) believed having the right to *Smoke* was a key factor in considering new housing. Half of student *consumers* wanted the right to *Own a Pet* to be a personal preference choice. A third of focus group *consumers* needed to be involved in *Community Decisions* that might affect their rights as consumers. Perhaps one consumer said it best. "It is all in choices. It comes down to whether I'm capable of choosing, and if it's tailored for me."

Affordability, Personality, and Security were the final categories identified by focus group participants as crucial consideration in future housing decisions. While there were no direct questionnaire choices that tapped consumer need in these areas, affordability can be indirectly measured by examining the responses to Question 11: *What decisions influenced choice of housing for consumer?* and Question 5: *Does the consumer receive public financial assistance? Cost*, as a determining factor in choosing current housing was selected by 68% of respondents. Another 13% chose their current housing based on the fact that it was *Subsidized*. Close to half of respondents (48%) claimed to be *Receiving Public Funds*. This number is probably understated, as 13% were unsure if they got these benefits. Many relied on government income subsidies such as

SSI (18%) and *SSDI* (13%). One male participant noted that many consumers "got their Social Security and they want their rent based upon their income and their income's not going to go up."

Theoretical Frameworks

Stress Theories. Stress theory maintains that stressors from the physical and social environments create a state of internal arousal or strain that has negative consequences on health (Miller, 1989). This study contends that the consumer is placed in a state of internal strain when subjected to limited options in housing choices and limited access to social stimulus. The findings of this study support this contention. As *consumers* and *general respondents* indicated, they want the choice to live in *Pleasant Neighborhoods*, have *Access to Community Activities*, and have privacy in daily activities. Only 27% of respondents were satisfied with current housing.

Consumers have many worries. First, they worry about safety. As one consumer pointed out, "People are often very distant from each other, unless they know each other for years. They just get very afraid." Further, they worry about being alone in their environment. One consumer stated, "I love having my own apartment, but still sometimes it gets lonely. If we had a place to go and play cards and exercise and games, then people would know about that room and be able to go down there. 'Cause they could be lonely in their apartments too." Another consumer's worry is transportation. According to the survey tool, 39% of the participants did not have a driver's license, so it makes sense that consumers need to be close to a public transportation source or to a metropolitan area. Understandably, *Access to Public Transportation* and *Close to Transpo* made the top-seven list in importance for future housing locale. One male stated that location was his

most important consideration in housing "because I ride the bus. That is the only way I can get around and I cannot walk that far, so a bus has to be top priority." Concerns also include feelings of insecurity in their financial status. They are financially and emotionally invested in their homes and they need to feel that what "you put into it over the years is what you can get out… and it can't be taken away." One consumer worried about what would happen to their housing if they were "not able to work." Another participant feared that he would "have to sign an agreement for X number of years" and "sign my social security receipts to a facility." Finally, consumers worry about maintaining their own individuality. As a women living at the Center for the Homeless put it, "It would be nice to say this is my place and I decorated it the way I wanted." Still another bemoaned the fact, "I share a room and it's kinda not very good because I don't get very good sleep."

Providing a Multilevel Clustered Housing Option that addresses all of these issues would alleviate some of the stressors identified by these consumers, reducing the negative consequences on health.

Social Support Theories. While the use of adjusted stressful life events scales has established a relationship between stressors and health in a variety of populations (Mohr et al., 2000) research has indicated that adequate social support appears to buffer the effects of stressful life events. This concept is essential to the precepts set forth in the Olmstead Act. The present findings supported this theory. Student *general respondents* listed being *Close to Family* as first priority in considering new housing. NAMI *consumers* agreed, with 60% making this choice. Socialization was one of the top seven responses given by focus group participants during group interview sessions. Consumers

need to feel understood. They need to know that there are other consumers nearby, who understand their mental health issues. Furthermore, they need to feel like they can "count on each other for help." Consumers need to feel a sense of belonging in the community. One woman summed up this longing in her statement. "I do like group home living because it's like a family." In summary, while consumers value their privacy they need one another and other people to feel safe, to avert loneliness, to feel understood, and to feel a sense of belonging. Providing a Multilevel Clustered Housing Option that addresses all of these issues would buffer some of the stressors identified by these consumers, reducing the negative consequences on health.

Coping Strategies. In the past, external pressure from society, via institutions, was placed on mental health consumers. This imposed external locus of control is being challenged. Allowing consumers a voice in housing and treatment options is imperative to Olmstead action success. Rapp (2000) argued that care and treatment of people with severe mental illness should include consumer empowerment. This current study demonstrates that consumers have much to say about their choice of housing. This study would argue that increasing the housing options for mental health consumers to accommodate for their defined needs, would provide an increased feeling of control, thereby, reducing stress, increasing coping, and enhancing well-being.

Focus group participants listed *Control* second only to *Privacy* in priority in deciding future housing. Questionnaire respondents need to feel that they have a say in choosing *Non-smoking* or *Smoking Units*. Half of student *consumers* wanted the right to *Own a Pet* to be a personal preference choice. Focus group *consumers* needed to be involved in *Community Decisions* that might affect their rights as consumers. Providing a

Multilevel Clustered Housing Option that includes consumer input would reduce the external pressures on the mentally ill that for so long has kept them institutionalized and without a voice in housing choice. As one consumer living at the Center for the Homeless put it, "What is showing up here is that the environment can help recreate the negative cycles in our lives." Conversely, empowering consumers to become involved in positive change is integral to mental wellness.

As we develop our St. Joseph County Consolidation Plan let us not ignore consumer input in interpretation of the New Freedom and Olmstead Initiatives. Past efforts in this area have resulted in pockets of isolation, via group homes and county homes, where consumers had little interaction with the community and neighborhood. The results of this study indicate that consumers are not opposed to living in close proximity to other consumers, rather they object to living in large state run facilities away from friends, family, and the opportunity to lead self-determined purposeful lives.

While there was overwhelming consensus that more housing is needed, there were differences in perception of the level of support needed between *consumers* and the *loved ones of consumers*. Explanations that might account for these differences include:

- The *consumers* that participated in this study were enrolled in Indiana University classes, NAMI support groups, or treatment classes at the Center for the Homeless or Madison Center. They may rely on support services to a lesser degree than the consumers identified by *loved ones* who were not involved in these programs.
- *Loved ones of consumers* may have a more objective viewpoint of the support needed to maintain stability, for example medication monitoring or money management, than *consumers* do.

What does seem clear is that there is a portion of chronically mentally ill individuals who rely on an intensive support system to maintain stability in the community. This need is not in conflict with the Olmstead Initiative, as it also advocates for consumers' rights to live in the most integrated setting appropriate to the needs of the individual. For many individuals the Clustered Model of Housing might be the most integrated community setting. For within this setting the consumer could find a sense of community yet have the freedoms offered to all Americans—the freedom to make choices, the right to privacy, and the freedom to express self—in a safe, affordable neighborhood.

The information from this study will be useful to local governmental officials and agency administrators for planning purposes, but will also be helpful to consumer advocates, neighborhood associations and civic groups. The common goal for consumers and those involved with them is for housing that respects and meets the personal as well as the variety of housing needs that all humans desire, including comfort, safety, convenience of services, social support, companionship, affordability, dignity, and self-determination.

On the basis of the positive reception of the proposed Clustered Housing model, this study suggests further research with regard to empowering consumer preference and housing design that reinforces a sense of community integration yet allows for a level of supportive services that is individualized according to consumer need. Recommendations include broadening the scope of this study to include service providers and the general public, so that all voices might weigh in on this issue.

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Table 1.

Consumer beds available in St. Joseph County in 2004

Housing	Beds
Center for the Homeless	191*
Portage Manor	144
Madison Center Apartments	74
Hope Rescue Mission	50**
Madison Center Group Homes	24
Total	483

Note. * This number reflects an average nightly bed count. This amount varies depending on how many children are in the family units. The Center for the Homeless beds are not reserved exclusively for mental health consumers. Surveys have estimated that up to 1/3 of their residents suffer mental illness. This study includes all beds available, thus over-estimating actual space.

** The Hope Rescue Mission serves homeless people without regard to diagnosis of mental illness, as long as residents follow the rules for residence. There is no evidence that their populations differ from other homeless institutions in the number of mentally ill patrons. This study includes all beds available, thus over-estimating actual space.

Table 2.

Study 2: Student Analysis of Important Considerations

For Future Housing for Consumers

Housing Considerations	*General Respondents*	*Consumers*
Air-conditioning	43.9%*	60.0%*
Pleasant Neighborhood	36.6%*	60.0%*
On-site Parking	12.2%	60.0%*
Washer and Dryer	36.6%*	50.0%*
Pets	34.1%	50.0%*
Private Phone	26.8%	50.0%*
On-site Recreation Area	26.8%	50.0%*
Private Residence	17.1%	50.0%*
Close to Family	53.7%*	30.0%
Money Management	51.2%*	30.0%
On-site Medical Care	22.0%	30.0%
Involvement in Community Activities	19.5%	30.0%
Smoking	14.6%	30.0%
Private Room	48.8%*	20.0%
Medication Monitoring	48.8%*	20.0%
On-site Dining	17.1%	20.0%
Kitchenette	9.8%	20.0%

table continues

Housing Considerations	*General*	*Consumers*
Security System	7.3%	20.0%
Involvement in Community Decisions	2.4%	10.0%
Access to Public Transportation	39.0%*	10.0%
Non-smoking Units	29.3%	10.0%
On-site Activities	26.8%	10.0%
Transpo Access	17.1%	10.0%
On-site Case Management	12.2%	10.0%
Close to Shopping	4.9%	10.0%
Shopping Assistance	2.4%	10.0%
Coin Laundry	0.0%	0.0%
Help Buttons	17.1%	0.0%
Close to Mental Health Facility	14.6%	0.0%
On-site Nursing	14.6%	0.0%
Grooming Assistance	12.2%	0.0%
Independence from Money Management	12.2%	0.0%
Shared Room with Storage Area	9.8%	0.0%
Handicap Accessible	9.8%	0.0%
Non-shared Personal Bathroom	7.3%	0.0%
Laundry Service	7.3%	0.0%
Independence from Medication Mgt.	4.9%	0.0%

Note. An * indicates that this item was listed within the top seven in importance when considering new housing for consumers.

Table 3.

Study 3: Focus Group Analysis of Important Considerations For Future Housing for Consumers

Housing Considerations	*General Respondents*	*Consumers*
Air-conditioning	37.5%	66.7% *
Own Washer and Dryer	50% *	60% *
Private Phone	62.5%*	46.7% *
Pleasant Neighborhood	12.5%	40% *
Close to Transpo	50% *	33.3% *
Private Residence	50% *	33.3% *
Involvement in Community Decisions	25.0%	33% *
Smoking	25.0%	33% *
Access to Public Transportation	50% *	26.7%
Private Room	25.0%	26.7%
Personal Kitchenette	25.0%	26.7%
Shopping Assistance	25.0%	20.0%
On-site Activities	25.0%	20.0%
On-site Recreation Area	37.5%	20.0%
Close to Shopping	37.5%	20.0%
Handicap Accessible	12.5%	20.0%
On-site Dining	12.5%	20.0%

table continues

Housing Considerations	*General*	*Consumers*
On-site Coin Laundry	50% *	20.0%
Pets	25.0%	20.0%
Money Management	37.5%	13.3%
Independence from Med Monitoring	12.5%	13.3%
Security System	50% *	13.3%
Community Activities	50% *	13.3%
Close Proximity to Family	12.5%	13.3%
Non-smoking	12.5%	13.3%
Private Parking	12.5%	6.7%
On-site Medical Care	25.0%	6.7%
Personal Bathroom	25.0%	6.7%
Independence from Money Mgt.	25.0%	6.7%
Close to Mental Health Facility	12.5%	6.7%
Laundry Service	12.5%	6.7%
On-site Nursing	25.0%	6.7%
On-site Case Management	12.5%	0.0%
Emergency Buttons	37.5%	0.0%
Shared Room	12.5%	0.0%
Grooming	12.5%	0.0%
Medication Monitoring	25.0%	0.0%

Note. An * indicates that this item was listed within the top seven items in importance when considering new housing for consumers.

Figure Captions

Figures 1a & 1b: Study 1. NAMI. Comparison of current housing status of NAMI *consumers* and *general respondents.*

Figures 2a & 2b: Study 1. NAMI. Comparison of the factors that influenced current housing choices of NAMI *consumers* and *general respondents.*

Figures 3a, 3b, & 3c: Study 1. NAMI. Comparison of Most Important Factors to Consider in New Housing responses of NAMI *consumers* and *general respondents.* Note that *consumers'* choices were divided evenly among many options.

Figures 4a & 4b: Study 1. NAMI. Comparison of Support for Clustered Housing responses of NAMI *consumers* and *general respondents.*

Figure 5: Study 2. Student. Current housing status for *general respondents* in student survey.

Figures 6a & 6b: Study 2. Student. Comparison of most important factors influencing current housing choices for student *consumers* and *general respondents.*

Figures 7a & 7b: Study 2. Student. Comparison of Most Important Factors to Consider in New Housing responses of Student *consumers* and *general respondents.*

Figures 8a & 8b: Study 2. Student. Comparison of Support for Clustered Housing responses of Student *consumers* and *general respondents.*

Figures 9a & 9b: Study 3. Focus Groups. Comparison of current housing status of Focus Group *consumers* and *general respondents.*

Figure 10a & 10b: Study 3. Focus Groups. Comparison of Current Use of Public Funds in Focus Group *consumers* and *general respondents.*

figure captions continued

Figure Captions

Figure 10a & 10b: Study 3. Focus Groups. Comparison of Current Use of Public Funds in Focus Group *consumers* and *general respondents.*

Figures 11a & 11b: Study 3. Focus Groups. Comparison of most important factors influencing current housing choices for Focus Group *consumers* and *general respondents.*

Figures 12a & 12b: Study 3. Focus Groups. Comparison of Most Important Factors to Consider in New Housing responses of Focus Group *consumers* and *general respondents.*

Figures 13a & 13b: Study 3. Focus Groups. Comparison of Support for Clustered Housing responses of Focus Group *consumers* and *general respondents.*

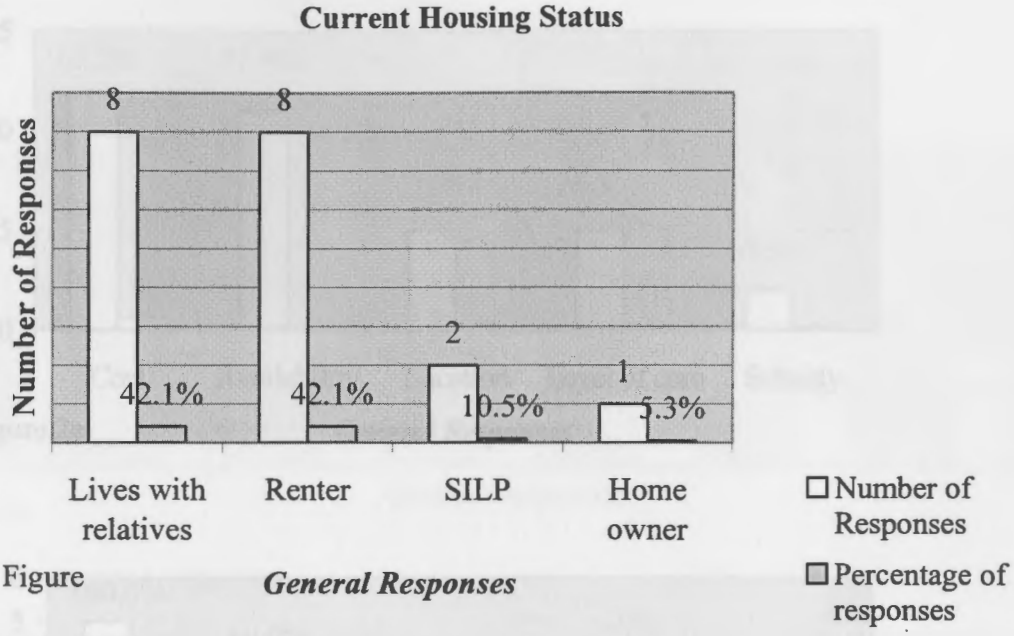


Figure ***General Responses***

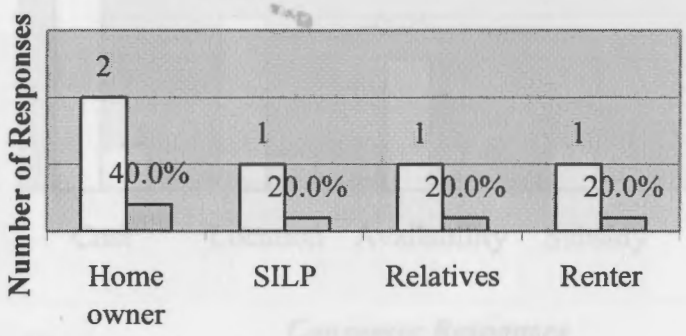


Figure 1b. ***Consumer Responses***

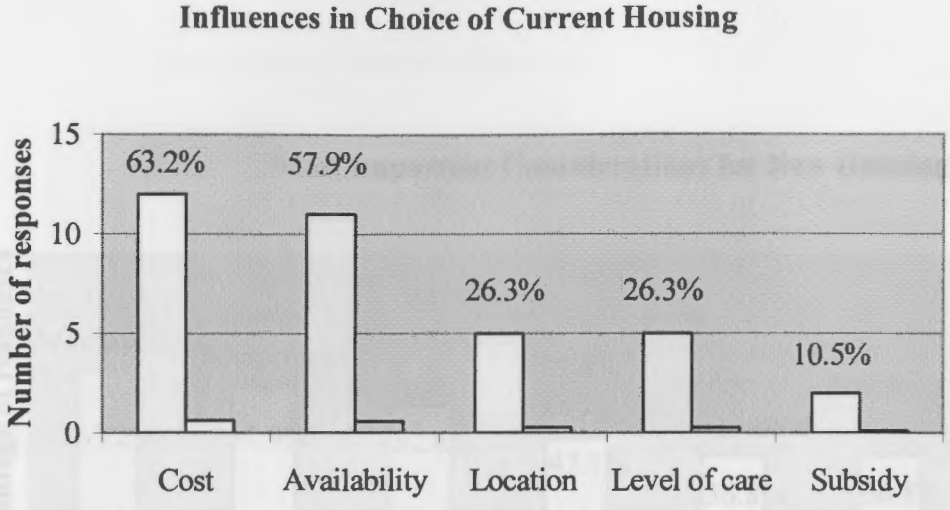


Figure 2a.

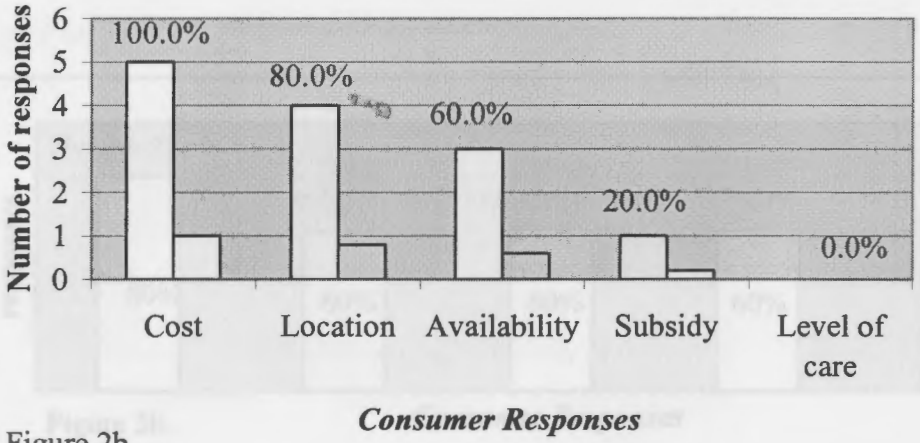


Figure 2b.

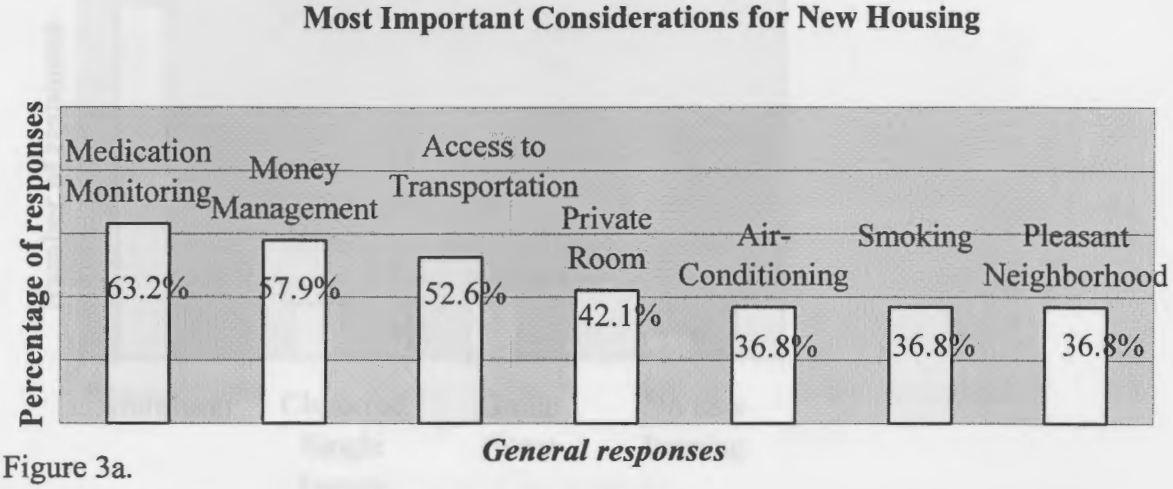


Figure 3a.

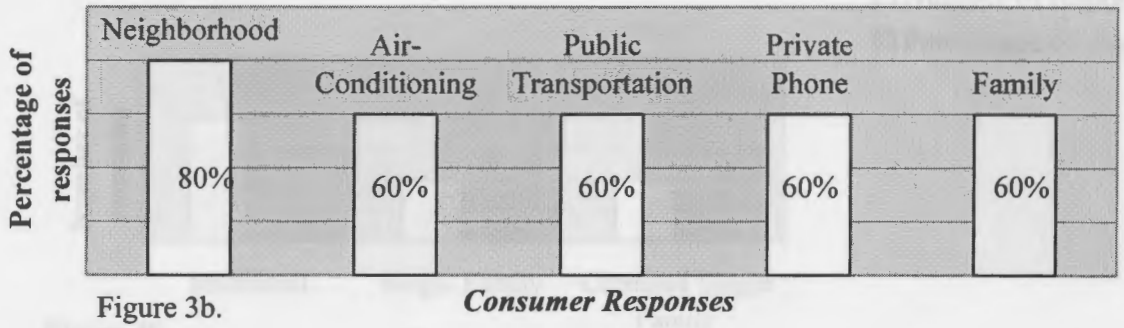


Figure 3b.

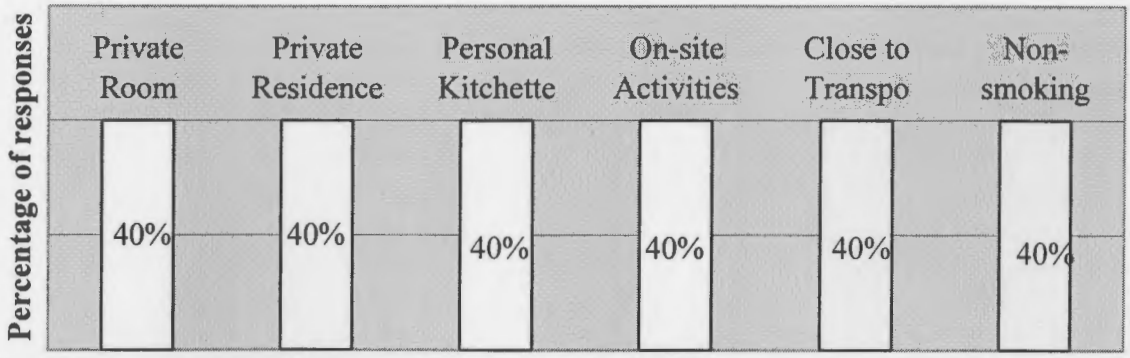


Figure 3c.

Consumers : Continued

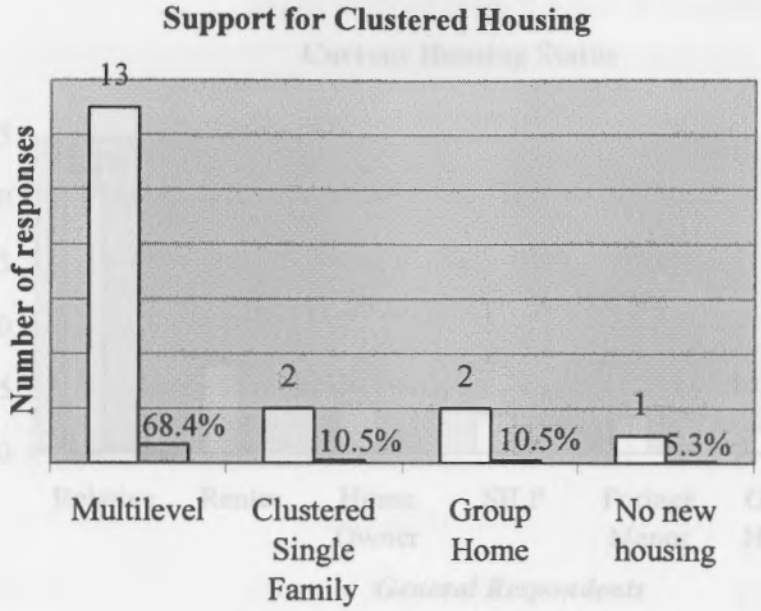


Figure 4a. ***General Respondents***

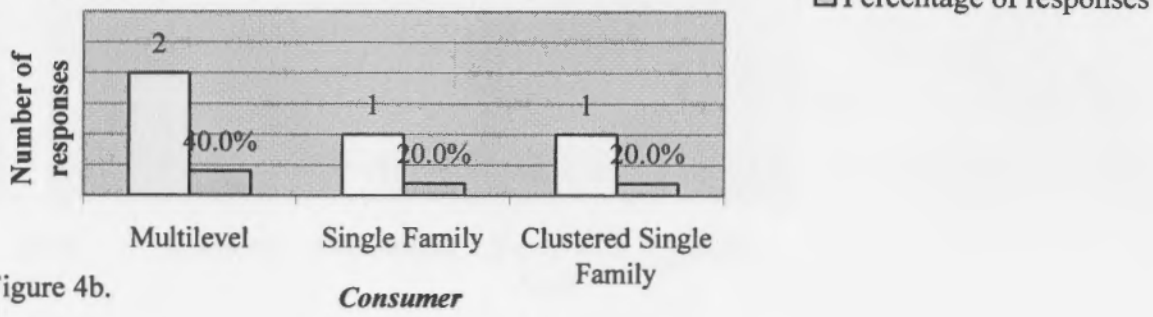
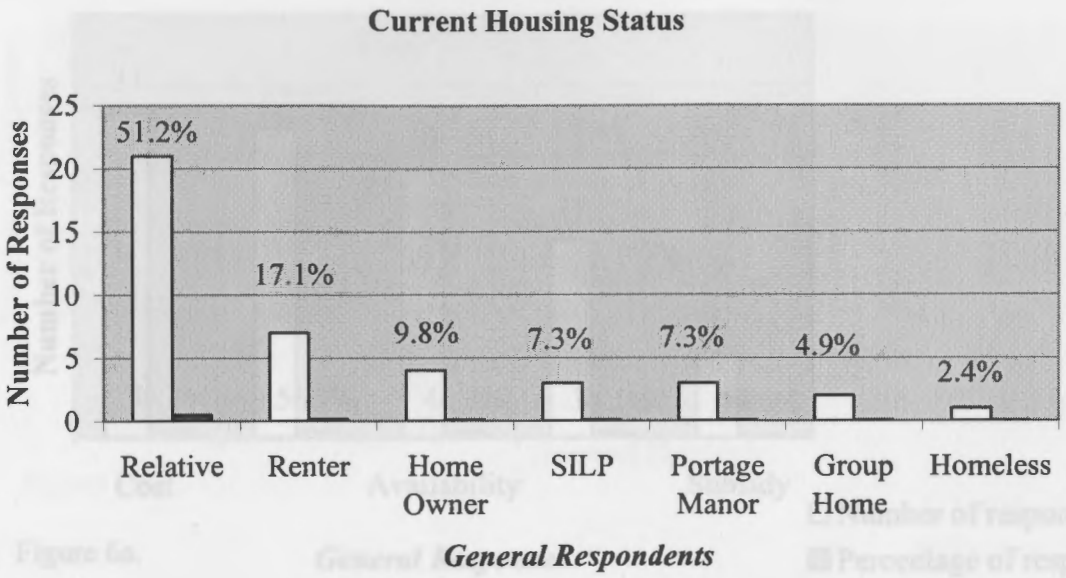


Figure 4b. ***Consumer***


Current Housing Status
Number of Responses
25
20
15
10
5
0
51.2%
17.1%
9.8%
7.3%
7.3%
4.9%
2.4%
Relative
Renter
Home Owner
SILP
Portage Manor
Group Home
Homeless
General Respondents

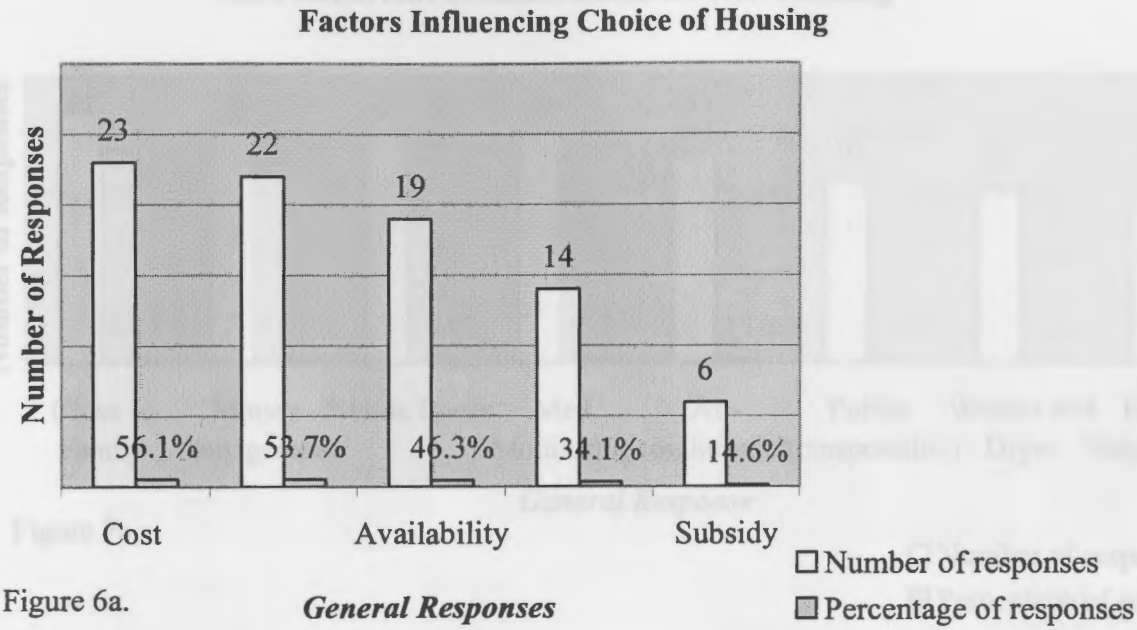


Figure 6a. ***General Responses***

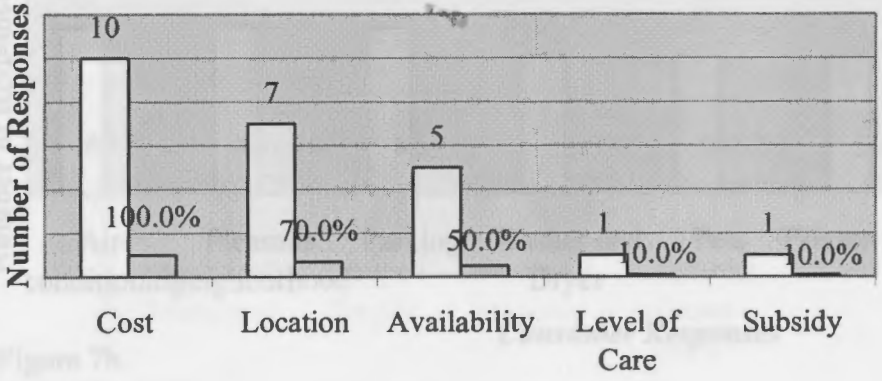


Figure 6b. ***Consumer***

Most Important Considerations for New Housing

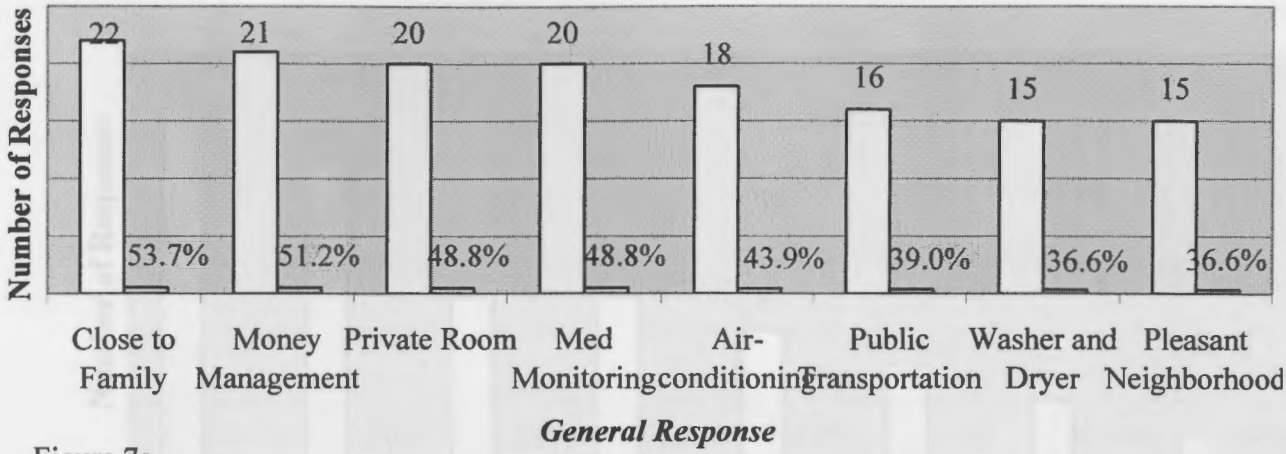


Figure 7a.

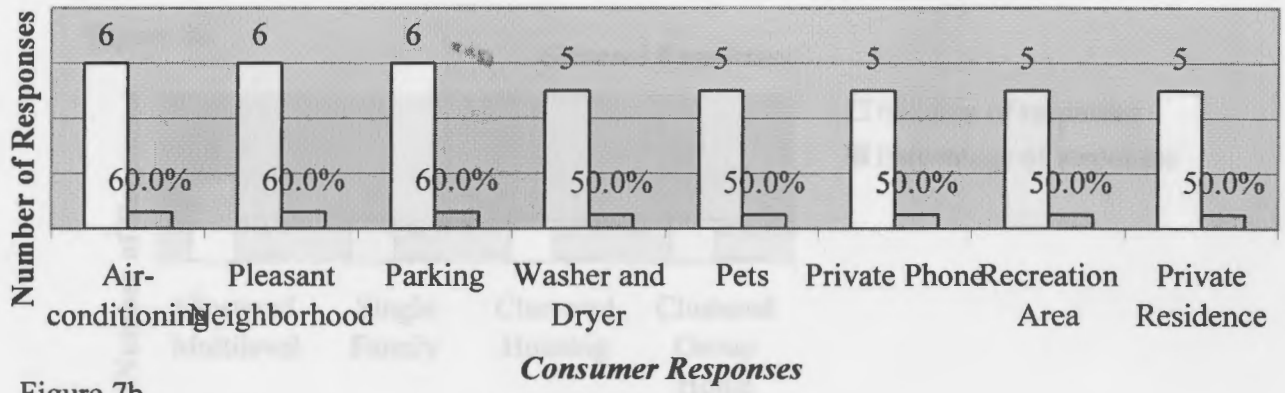


Figure 7b.

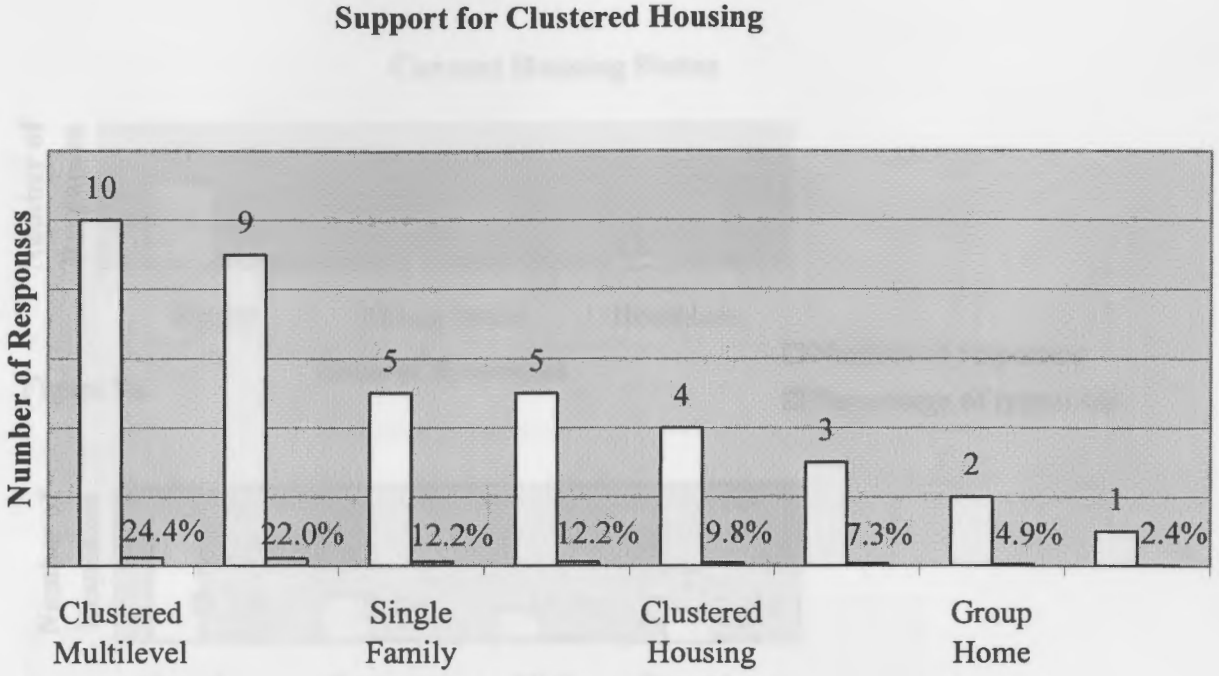


Figure 8a.

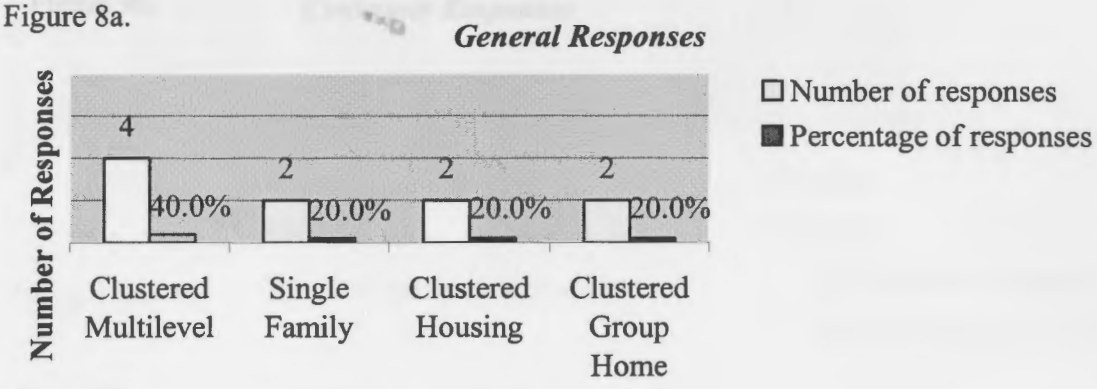


Figure 8b.

Consumer Responses

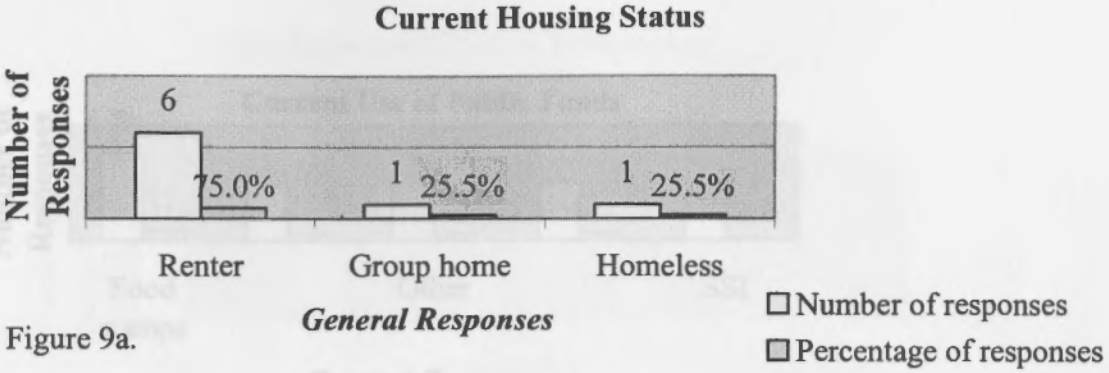


Figure 9a.

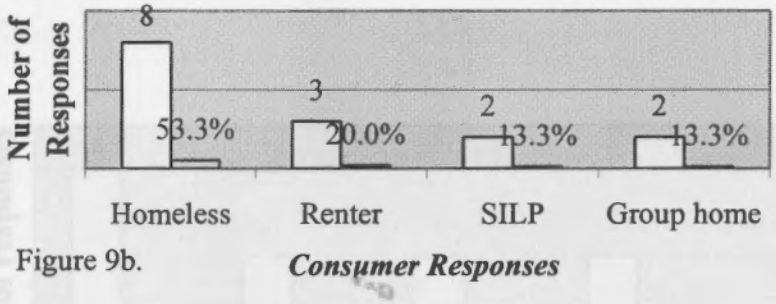
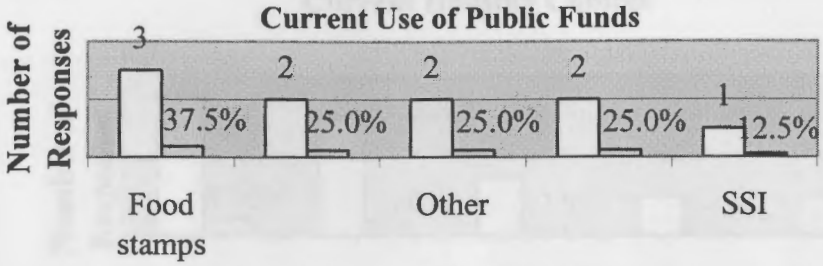
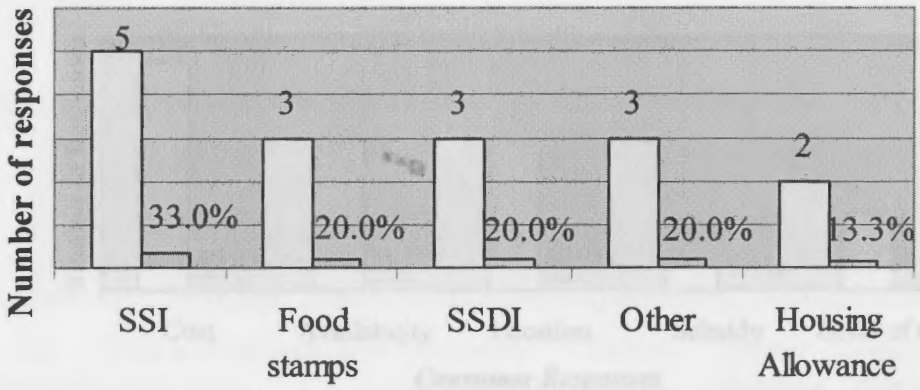


Figure 9b.



General Responses

Figure 10a.



Consumer Responses

Figure 10b.

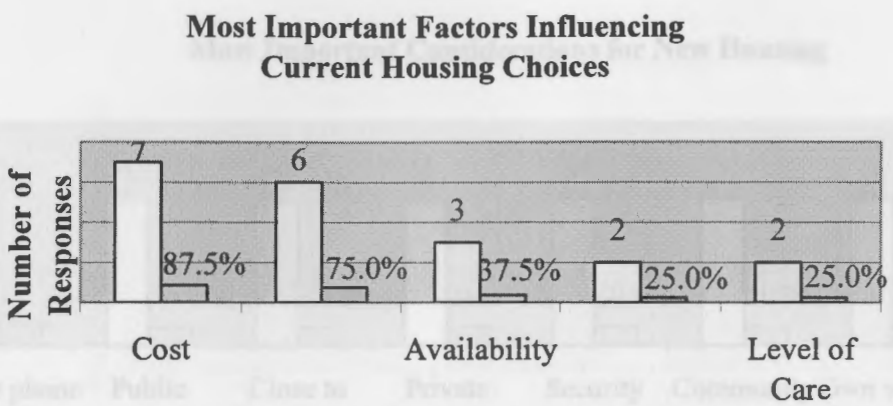


Figure 11a.

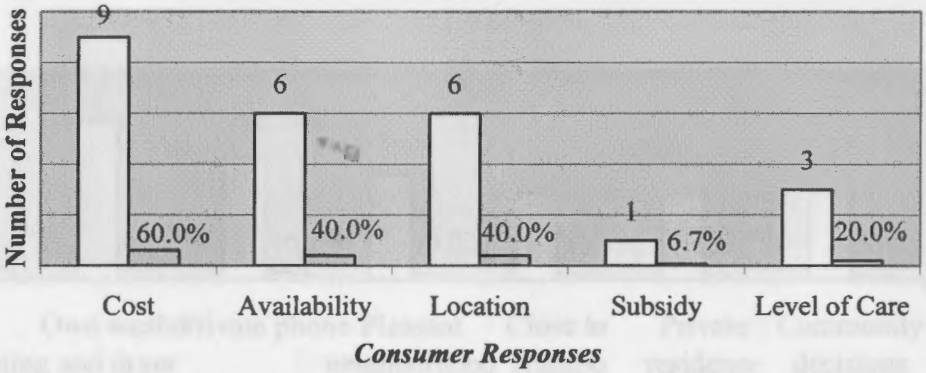


Figure 11b.

☐ Number of responses
☐ Percentage of responses

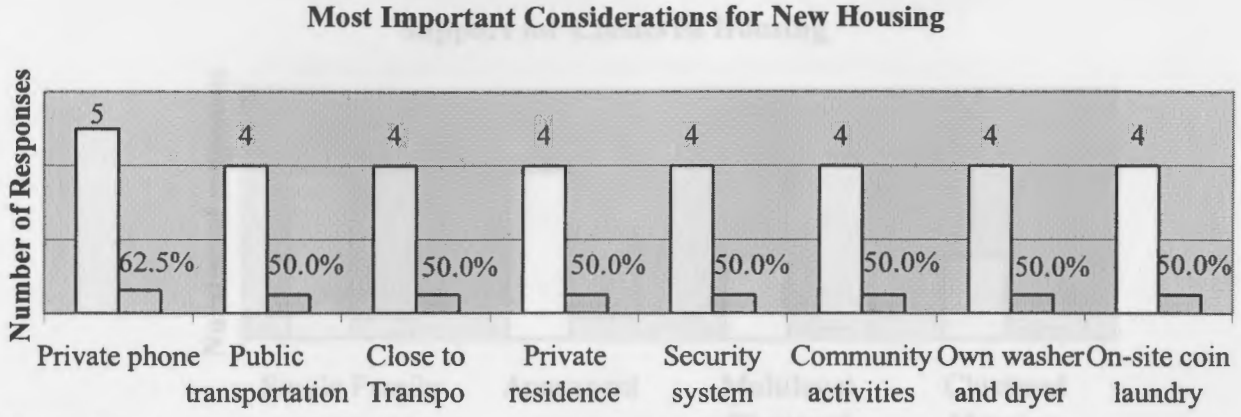


Figure 12a.

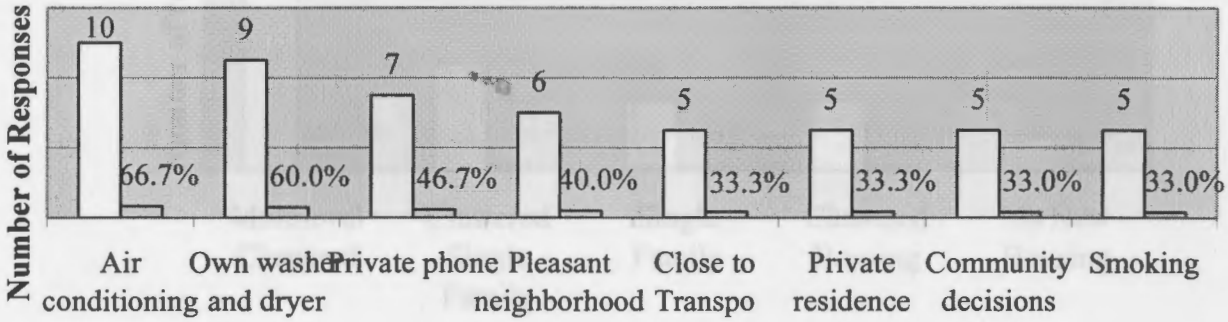


Figure 12b.

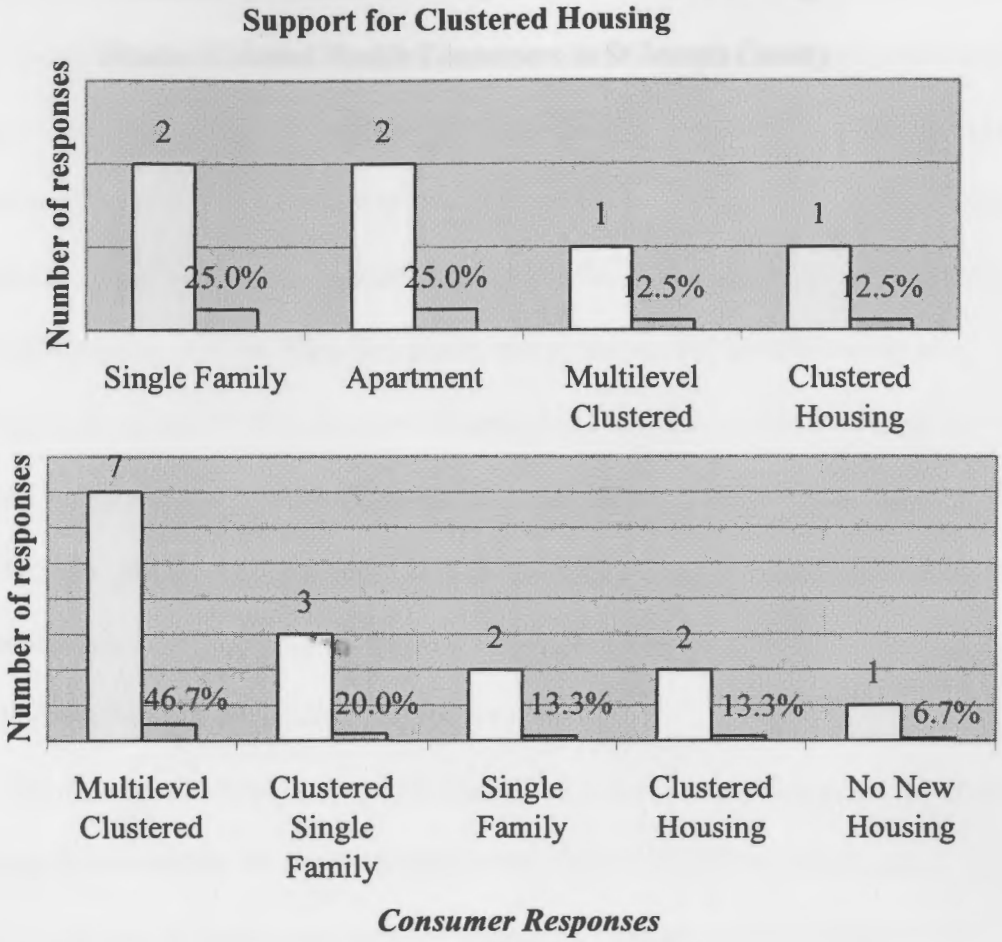


Figure 13b.

☐ Number of responses
☐ Percentage of responses

Appendix A

Consumer Satisfaction Survey: Assessment of Housing Needs of Mental Health Consumers in St Joseph County

Consumer Satisfaction Survey:

Assessment of Housing Needs of Mental Health Consumers in Saint Joseph County

Having worked with the chronically mentally ill for many years, awareness of the shortage of quality housing for mentally ill residents in St. Joseph County has increased. Fortunately, I am not the only one that shares concern over the current housing situation. Indiana State Legislature is pushing for solutions to the dilemma posed by the Olmstead v. L.C (1999) ruling that specifies that goods and services shall be afforded to an individual with a disability "in the most integrated setting appropriate to the needs" of the individual. (paragraph 1) Interpretation of that legislation has varied from region to region. In 2001, public meetings were held in South Bend to address current efforts in implementation of *Indiana's Comprehensive Plan for Community Integration and Support of Persons with Disabilities* in our area (2001).

This survey was designed in consultation with the Master of Applied Psychology program at IUSB and the National Alliance of the Mentally Ill (NAMI) to assess community interest in housing options for mentally ill residents of St. Joseph County. Completing the survey should take approximately five minutes. Your responses will be held in complete confidence. Please complete the survey questionnaire and return it in the stamped addressed envelope within five days. The knowledge gained from this survey will help develop ideas for improving service to your community. Thank you for your time and cooperation.

Merinell Heines-Thomas
Indiana University South Bend

A consumer of mental health services is an individual who has been diagnosed with a DSM-IV mental illness or has been treated for a mental illness within the past five years.

1. How would you describe yourself.
(Check all that apply)

1. ☐ Mental health service consumer
2. ☐ Guardian of consumer
3. ☐ Family member of consumer
   a. ☐ Mother
   b. ☐ Father
   c. ☐ Sibling
   d. ☐ Spouse
   e. ☐ Other
4. ☐ Friend of Consumer

2. What is the consumer's current housing status?

1. ☐ Independent Living
   a. ☐ Home owner
   b. ☐ Renter
2. ☐ Supported Independent Living (SILP)
3. ☐ Living with a relative
4. ☐ Resident of a Group home
5. ☐ Portage Manor resident
6. ☐ Share residence with a friend
7. ☐ Homeless (residing in a shelter)

3. How many people reside with the consumer?

1. ☐ Consumer only
2. ☐ 2 people
3. ☐ 3-5 people
4. ☐ More than 5 people

4. Does the consumer have a driver's license?

☐ Yes ☐ No

1. What is the consumer's gender?

a. ☐ Male
b. ☐ Female

2. What is the consumer's age?

a. ☐ Under 18
b. ☐ 18- 29
c. ☐ 30-39
d. ☐ 40-49
e. ☐ 50-59
f. ☐ 60 +

3. What is the consumer's race?

a. ☐ White
b. ☐ Black
c. ☐ Hispanic
d. ☐ Asian
e. ☐ Mixed race
f. ☐ Native American
g. ☐ Other

5. Does the consumer receive public financial assistance?

a. ☐ Yes b. ☐ No c. ☐ Do not know

6. If you answered 'Yes' to question 5, check the types of financial assistance received.

1. ☐ Housing allowance
2. ☐ Food stamps
3. ☐ SSI
4. ☐ SSDI
5. ☐ ARCH
6. ☐ Vocational Rehabilitation Vouchers
7. ☐ Other (Please specify)

_____

7. Does the consumer receive financial housing assistance?

a.☐ Yes b.☐ No c.☐ Do not know

8. If you answered 'yes' to question 7, indicate the type of assistance received.

☐ Housing Authority Subsidy
☐ Section 8
☐ Vocational Rehabilitation Vouchers
☐ Other (Please specify)

_____

9. Which of the items listed below would be important to include in future housing decisions for the consumer?
(Check all that apply)

1. ☐ Access to public transportation systems
2. ☐ Close proximity to Transpo/bus stop
3. ☐ Private parking area
4. ☐ On-site medical care
5. ☐ On-site Case Management
6. ☐ Emergency help buttons
7. ☐ Personal space (check one)
   a. ☐ Private room
   b. ☐ Shared room with a private storage space
   c. ☐ Private residence
   d. ☐ Personal non-shared bathroom
8. ☐ Assistance with basic grooming/bathing
9. ☐ Shopping assistance
10. ☐ Money management
11. ☐ Medication monitoring
12. ☐ Independence from money management
13. ☐ Independence from medication monitoring
14. ☐ Private phone line
15. ☐ Security system
16. ☐ On-site activities
17. ☐ Recreation area
18. ☐ Access to community activities
19. ☐ Involvement with community decisions
20. ☐ Close proximity to family
21. ☐ Close proximity to shopping mall
22. ☐ Handicap accessibility
23. ☐ Close proximity to mental health facility
24. ☐ On-site dining room/food service
25. ☐ Personal kitchenette
26. ☐ Laundry
    a. ☐ Own washer and dryer
    b. ☐ On-site coin laundry facility
    c. ☐ Laundry service
27. ☐ On-site nursing
28. ☐ Air conditioning
29. ☐ Allowance of pets
    a.☐ Yes b. ☐ No
30. ☐ Smoking
31. ☐ Non-smoking units
32. ☐ Pleasant neighborhood

10. How satisfied is the consumer with current housing?

1. ☐ Very satisfied
2. ☐ Somewhat satisfied
3. ☐ Somewhat unsatisfied
4. ☐ Very unsatisfied
5. ☐ Do not know

11. What decisions influenced choice of housing for consumer?

(Check all that apply)

1. ☐ Cost
2. ☐ Availability
3. ☐ Location
4. ☐ Level of care
5. ☐ Subsidy

12. Which of the items listed below would be important to include in future housing decisions for the consumer?

(Check all that apply)

1. ☐ Access to public transportation systems
2. ☐ Close proximity to Transpo/bus stop
3. ☐ Private parking area
4. ☐ On-site medical care
5. ☐ On-site Case Management
6. ☐ Emergency help buttons
7. ☐ Personal space (check one)
   a. ☐ Private room
   b. ☐ Shared room with a private storage space
   c. ☐ Private residence
   d. ☐ Personal non-shared bathroom
8. ☐ Assistance with basic grooming/bathing
9. ☐ Shopping assistance
10. ☐ Money management
11. ☐ Medication monitoring
12. ☐ Independence from money management
13. ☐ Independence from medication monitoring
14. ☐ Private phone line
15. ☐ Security system
16. ☐ On-site activities
17. ☐ Recreation area
18. ☐ Access to community activities
19. ☐ Involvement with community decisions
20. ☐ Close proximity to family
21. ☐ Close proximity to shopping mall
22. ☐ Handicap accessibility
23. ☐ Close proximity to mental health facility
24. ☐ On-site dining room/food service
25. ☐ Personal kitchenette
26. ☐ Laundry
    a. ☐ Own washer and dryer
    b. ☐ On-site coin laundry facility
    c. ☐ Laundry service
27. ☐ On-site nursing
28. ☐ Air conditioning
29. ☐ Allowance of pets
    a. ☐ Yes b. ☐ No
30. ☐ Smoking
31. ☐ Non-smoking units
32. ☐ Pleasant neighborhood

CLUSTERED HOUSING OPTION:

Other communities have adopted clustered housing options for special populations. Clustered housing refers to individual housing units that are in close proximity to other similar units. An example of clustered housing is a senior retirement community. They may or may not have on-site staff.

12. If new housing for mental health consumers were built in your area, which of these options would you prefer: (Please choose only one).

1. ☐ I would prefer a housing complex consisting of individual units in close proximity to each other. Six to eight consumers would share each unit. Mental health services and support staff would be available on-site, but in a separate facility. This model is similar to a **retirement community model** with several consumer **group homes** clustered together.

2. ☐ I would prefer a housing complex consisting of individual housing units in close proximity to other units, with 24 hr. in-house support staff. This option is the same as in #1, except support staff would stay in each home and provide 24 hr. supervision.

3. ☐ I would prefer housing units for mental health consumers that are not close to other units housing mental health consumers. Six to eight consumers would share each unit. This model is similar to the **group home** concept and would provide 24 hr. on-site supervision.

4. ☐ I would prefer a secure apartment building that houses mental health consumers, exclusively, with live in staff.

5. ☐ I would prefer single family dwellings integrated within the community with case management services and on-call care.

6. ☐ I would prefer a housing complex consisting of single-family dwellings for consumers. Other consumer's homes would be close by. Support staff would be housed separately, on-site. This is the same as # 1, except the homes would be single-family dwellings instead of group homes.

7. ☐ I would prefer a multilevel care housing complex consisting of a combination of the above housing options that would allow for a continuum of care. Some units would having 24 hr. supervision and others on-call care support staff, per need of the consumer. Single-family home options, as well as the group home alternative would be available.

8. ☐ I do not support new housing being built for the mentally health consumers.

Thank-you for your support of this project.

Appendix B

Informed Consent Form: Study 1. NAMI

IUSB INFORMED CONSENT STATEMENT FORM

Mental Stability and Environmental Stressors
Clustered Housing Needs Assessment

STUDY PURPOSE:

You are invited to participate in a research study, entitled *Mental Stability and Environmental Stressors Clustered Housing Needs Assessment*. The purpose of this study is to assess the housing needs of mental health consumers in St. Joseph County. To ensure your confidentiality please place the completed questionnaire in the envelope marked Questionnaire and your signed Informed Consent Form in the other envelope. In that way there will be no way to track individuals' responses. The envelopes are pre-addressed and stamped.

The information gained from this research will assist in the development of a comprehensive plan for housing the disabled in our community. Currently, there are waiting lists for all available accommodations. The Center for the Homeless turns away approximately 12 applicants each month, due to a shortage of beds. Similarly, Hope Rescue Mission is filled to capacity and cannot accept new tenants. There are waiting lists for subsidized housing, group homes, and residential facilities, such as Portage Manor. The state of Indiana is struggling to keep up with the demand for housing needs for the disabled. Your input is invaluable in the effort to provide consumers with affordable, needed housing.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to participate in this research study. I understand that I may drop out of the study at any time. I acknowledge receipt of a copy of this informed consent statement.

SUBJECT'S SIGNATURE_____

DATE_____

Merinell Heines-Thomas
Master of Applied Psychology
(574) 280-4602 Watw1000@aol.com

Appendix C

Invitation to Participate Form

Study 2. Student survey

INVITATION TO PARTICIPATE

Mental Stability and Environmental Stressors:
Clustered Housing Needs Assessment

STUDY PURPOSE:

You are invited to participate in a research study, entitled *Mental Stability and Environmental Stressors Clustered Housing Needs Assessment*. The purpose of this study is to assess the housing needs of mental health consumers in St. Joseph County.

STUDENT QUALIFICATIONS TO PARTICIPATE:

The study will be limited to students that: (1) are mental health service consumers, (2) have family members that are mental health service consumers, or (3) have close friends that are mental health service consumers. The consumer must have received services within the past five years, from an agency that provides mental health services.

PROCEDURE FOR THE STUDY:

You will be asked to complete a short questionnaire and return it to the researcher for 10 points of extra credit. Your identity and expressed opinions will be kept confidential. To ensure confidentially, completed questionnaires will be placed in a sealed envelope and placed in a specially marked box in the Psychology Lab Office. No names will appear on the questionnaire. A separate box will be provided for *Informed Consent Forms*. The informed consent form will have a space for student identification number and extra credit will be posted to that number.

For more information or if you have additional questions, I can be reached at:

Merinell Heines
(574) 280-4602

THANK-YOU

Appendix D

Informed Consent Form

Study 2. Student survey

Indiana University South Bend
INFORMED CONSENT STATEMENT FORM

Mental Stability and Environmental Stressors:
Clustered Housing Needs Assessment

STUDY PURPOSE:
You are invited to participate in a research study, entitled *Consumer Satisfaction Survey: Assessment of Housing Needs of Mental Health Consumers in St. Joseph County.* The purpose of this study is to assess the housing needs of mental health consumers in St. Joseph County.

STUDENT QUALIFICATIONS TO PARTICIPATE:
The study will be limited to individuals that: (1) are mental health service consumers, (2) have family members that are mental health service consumers, or (3) have close friends that are mental health service consumers. The consumer must have received services within the past five years, from an agency that provides mental health services.

PROCEDURE FOR THE STUDY:
You will be asked to complete a short questionnaire and return it to the researcher. Your identity and expressed opinions will be kept confidential. No names will appear on the questionnaire. The data will be analyzed and combined with information gained from surveys conducted at Indiana University with students and focus groups at the Center for the Homeless.

PARTICIPANT'S CONSENT:
In consideration of all of the above, I give my consent to participate in this research study. I understand that I may drop out of the study at any time.
I acknowledge receipt of a copy of this informed consent statement.

PARTICIPANT'S SIGNATURE_____

DATE_____

For more information or if you have additional questions, I can be reached at:
Merinell Heines-Thomas: (574) 280-4602

THANK-YOU

Appendix E

Debriefing Form

Study 2. Student survey

DEBRIEFING FORM

Mental Stability and Environmental Stressors

Clustered Housing Needs Assessment

Thank-you for participating in this project.

The information gained from this research will assist in the development of a comprehensive plan for housing the disabled in our community. Currently, there are waiting lists for all available accommodations. The Center for the Homeless turns away approximately 12 applicants each month, due to a shortage of beds. Similarly, Hope Rescue Mission is filled to capacity and cannot accept new tenants. There are waiting lists for subsidized housing, group homes, and residential facilities, such as Portage Manor. The state of Indiana is struggling to keep up with the demand for housing needs for the disabled. Your input is invaluable in the effort to provide consumers with affordable, needed housing.

Merinell Heines-Thomas
Master of Applied Psychology
(574) 280-4602

Appendix F

Focus Group Topic Guide

Study 3. Focus groups

Focus Group Topic Guide

Welcome statements and introduction of moderator and assistant.

I. Introduction to study

II. Current Housing Options

1. What do you see as good housing?
2. Why are those things important to you?
3. Would you live in housing that does not meet your expectations?
4. What roles does funding play in your expectations?
5. How important is location when considering housing needs?
6. How important is proximity to health care services in your decision?
    a. Hospital/Medical services
    b. Mental Health services
7. Do you prefer to live close to others who have similar needs?

III. Describe what you see as the most important considerations for future housing.

IV. Present Clustered Housing Model

1. Advantages of this model
2. Disadvantages to this model

Appendix G

Informed Consent Form

Study 3. Focus groups

IUSB INFORMED CONSENT STATEMENT FORM

Mental Stability and Environmental Stressors
Clustered Housing Needs Assessment

STUDY PURPOSE:

You are invited to participate in a research study, entitled *Mental Stability and Environmental Stressors Clustered Housing Needs Assessment*. The purpose of this study is to assess the housing needs of mental health consumers in St. Joseph County. If you agree to participate, you will be one of approximately 6-7 focus group members who will be participating in this research.

PROCEDURE FOR THE STUDY:

The researcher and the research assistant will lead a discussion to assess housing preferences and explore available housing options. Feedback on the clustered housing alternative will be gathered. Research assistants will organize and aid in analyzing the information resulting from this study.

CONFIDENTIALITY:

Your identity and expressed opinions will be kept confidential.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to participate in this research study. I understand that I may drop out of the study at any time.

I acknowledge receipt of a copy of this informed consent statement.

SUBJECT'S SIGNATURE_____

DATE_____

SIGNATURE OF WITNESS _____

THANK-YOU